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LOSING A MILLION MINDS: CONFRONTING THE TRAGEDY OF ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

Contractor Documents

Part 3:
Special Care Programs and Facilities

March 1987

Designing a Residential Care Unit for Persons with Dementia, Dorothy H. Coons, Institute of Gerontology, University of Michigan, Ann Arbor, Michigan 48109

The Senior Respite Care Program, Louise Dunn, Senior Respite Care Program, Good Samaritan Hospital and Medical Center, Portland, Oregon 97210

Experiences of the Atlanta Area ADRDA in the Development and Management of the Community Services Program, Carolyn J. French, Atlanta Area Chapter, Alzheimer's Disease and Related Disorders Association, Atlanta, Georgia 30340

The Family Respite Center: Day Care for the Demented, ~~Lyn~~ LIN E. Noyes and Richard Wittenborn, Family Respite Center, Inc., Falls Church, Virginia 22043

The Family Survival Project, Diana M. Petty, Family Survival Project, San Francisco, California 94115

Evaluation of a 24-hour Care System for Persons with Alzheimer's and Related Disorders, J. Daniel Sands and Judy Belman, Harbor Area Adult Day Care Center, Costa Mesa, California 92627

Institutional Approaches to the care of Individuals with Dementia, Audrey S. Weiner, The Hebrew Home for the Aged at Riverdale, Riverdale, New York 10471

Urinary Incontinence in Alzheimer's Disease, Thelma J. Wells, School of Nursing, University of Michigan, Ann Arbor, Michigan 48109

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DESIGNING A RESIDENTIAL CARE UNIT
FOR PERSONS WITH DEMENTIA

by

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Designing a Residential Care Unit for Persons with Dementia*

By Dorothy Coons

This paper will advocate the need for a new approach to care for persons with dementia and will describe the inadequacies and inappropriateness of the current health care system to accommodate the special needs of this rapidly growing group of impaired elderly persons. It will further describe a two-year demonstration project for persons with dementia. This specially designed residential care model, called Wesley Hall, demonstrated that it is possible to provide a quality of life for impaired persons that enable them to continue to function maximally and achieve life satisfaction.

The person with Alzheimer's disease or other dementing illnesses has been described principally in terms of loss of cognitive abilities and functional capacities. Treatment has focused on ways to control behavior considered symptomatic of dementia. The inadequacies of our system of care to meet the special needs of this group of people emerged as a part of a national study by the Institute of Gerontology entitled Alzheimer's Disease: Subjective Experiences of Families (Coons et al., 1983). One part of this study dealt with the experiences that families had had in finding a nursing home to care for a relative.

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*Other project staff of the Institute of Gerontology, the University of Michigan, who were involved in the development, administration, staff training, and evaluation of Wesley Hall included Anne Robinson, Director of Wesley Hall Project; Beth Spencer, Program Consultant, and Shelly E. Weaverdyck, Neuropsychology Consultant. The physician for the project was James F. Peggs, M.D., Medical Director, University of Michigan Family Practice Center and the Chelsea United Methodist Retirement Home.

The most common problem mentioned by families was lack of available beds in nursing homes. However, perhaps more surprising and disturbing was the finding that almost one third of those families said their relatives were not accepted by institutions to which they applied. Some found that the label of Alzheimer's disease immediately caused problems with placement; and one woman reported that her husband was rejected by all nursing homes in the community after he became combative and was forced to leave one home. This study was completed in June 1983; many long-term care institutions at that time apparently believed that people with Alzheimer's disease were potentially difficult and created management problems, and rejected them on the basis of diagnosis.

Within the short period from June 1983 to the present, the health care system has become well aware of the large number of potential clients among this group and the importance of designing residential facilities designated for their care. Many health professionals are recognizing that our current system should be re-examined and new directions explored in meeting the needs of this unique group of elderly persons.

BEYOND DIAGNOSIS

The project described in this paper rejects the diagnosis of dementia, in itself, as incomplete and, at times, a hindrance to the development of appropriate interventions. This diagnosis, in the medical context, denotes brain damage and is often viewed as untreatable and carries with it the prognosis of inevitable deterioration.

In his discussion of psychosocial and environmental approaches to the care of elderly persons with dementia, Lawton (1980) states, "Anyone who has worked with OBS (organic brain syndrome) patients recognizes that by no means all behavior or affective disabilities seen in this group are the direct result of brain damage. Some may be unrelated to the organic condition, while others may be more disabling than they should be." He identifies this "excess disability" as occurring in "situations where the magnitude of the disturbance of functioning is greater than might be accounted for by basic physiological illness or cerebral pathology. . . Thus,. . . the excess disability may be susceptible to 'cure'." Brody (1973) in discussing excess disabilities states that the diagnostic label of dementia "should indicate treatment intervention, not benign neglect."

In describing the factors to which the severity of the clinical manifestations of senile brain disease are related, Pfeiffer (1977) lists the complexity and the friendliness or hostility of the environment as having impact. He states, "within broad limits, a stable, friendly, relatively simple environment, placing few demands on the individual, will tend to minimize the likelihood of associated psychopathologies. On the other hand, intellectually demanding and emotionally hostile environments tend to evoke maladaptive psychological responses, such as paranoid reactions, overt anxiety, depression, aggressive or assaultive behavior, and noncooperative behavior."

As greater consideration is given to the impact of environmental factors on behaviors, there also needs to be a reexamination of the objectives of treatment as they relate to the mentally impaired elderly. Hodge (1984) argues that "since the goal with most dementing patients is to maximize their quality of life, rather than expect a return to predemented levels of functioning, even small gains may be of considerable importance to the individual."

THE UNMET NEEDS OF THE PERSON WITH DEMENTIA

This paper will focus specifically on the special needs of persons with Alzheimer's disease or other dementias who are still active and relatively well physically. These people are unable to manage in retirement homes where many presently reside. However, the traditional nursing home is not an appropriate solution. Perhaps the following composite description of this group of underserved elderly will illustrate the dilemma.

Mr. C., a successful business man now in his late 70's, was well respected in his community and by his colleagues. He, his wife and three children had a close relationship and a large network of friends.

Several years ago, Mr. C. began to have problems managing simple tasks that had been routine for him. After a series of tests by a neurologist, he was given a diagnosis of senile dementia of the Alzheimer type. His wife was physically frail and unable to manage, and he was, therefore, placed in a nearby retirement home.

During the next six months, he became increasingly impaired. Some of his problems included: difficulty in locating the dining room, the bathroom, and his own room; inability to identify his wife or his children; agitation during most of his waking hours especially in a social gathering with residents from the retirement home; angry outbursts and verbal abuse for no apparent reason; urinating in inappropriate places; and combativeness with staff when they approached him about baths or attempted to help him locate the bathroom. He became the target of the resentment and hostility of residents who were intact, and his response was rage and verbal abuse.

Typically, these aggressive behaviors would place Mr. C. in jeopardy of placement in the traditional nursing home setting. If admitted, he would be labeled as a hostile, uncooperative and combative person, and a severe management problem. He would quickly become the recipient of heavy dosages of medication and physical restraints. As a result of the medication, he would become docile and withdrawn, almost totally unaware of his surroundings. He would no longer be able to respond, and he would spend most of his day slouched in a chair from which he could not escape. Or, if his body rejected the medication, he might become even more agitated and combative, making him totally unacceptable to the facility.

The project described here has demonstrated that it is possible to design a residential care setting that will help Mr. C. to continue to function and get pleasure from his involvement. Supportive and flexible staff approaches, not medication and physical restraints, become the interventions which reduce the frequency of the behaviors unacceptable in the retirement home. In addition, the milieu enables Mr. C. to maintain, to a great extent, the personality which endeared him to family and friends.

ISSUES SHAPING NEW MODELS OF CARE

A number of nursing and retirement homes around the country are now testing new environmental designs and new approaches in the care of persons with dementia. There are controversial issues related to what conditions can provide the most supportive environment and offer improved quality of life. Several of those issues are discussed below.

Separation Versus Integration

One of the most controversial issues among health care specialists is whether special living areas should be established for persons with severe memory loss, or whether they should be integrated with persons who are rational.

Administrators often cite the financial and logistical problems of organizing treatment according to needs. The "empty-bed," thus, becomes the prevailing factor in the placement of persons in many treatment settings in this country.

The arguments against the separation of persons according to needs are many. Some researchers believe that it is reasonable to expect the alert elderly person to help an impaired roommate or neighbor on a regular basis, this in spite of the fact that even staff sometimes find such assistance stressful and difficult. Such a policy creates intolerable suffering for the alert resident who is forced to live in close proximity with someone severely impaired who is often times barely more than an acquaintance.

The person with dementia is also inevitably harmed in such situations. Meacher (1972), reporting on some of the cruel treatment toward and rejection of the impaired older person by rational neighbors, speaks of the "isolationist spiral in which a person, once identified as eccentric or 'confused,' is increasingly ignored and then in seeking to adjust to growing isolation has recourse to the limited avenues of self-expression left which, being probably of an unusual or 'anormic' nature, then supply a 'logical' justification for even firmer rejection."

Another frequently expressed argument in favor of integration is that the intact persons can serve as models for those with severe memory loss. The circumstances which led to the designing of the project described in this paper refutes that argument from two perspectives. Firstly, it seems unrealistic to assume that the impaired elderly have the capacity to use the behaviors of other persons as prototype for their own responses. Secondly, alert persons who find themselves angry, frustrated, and unable to cope with their impaired neighbors will probably provide poor behavioral models.

An articulate resident voiced what appears to be a common feeling, "I don't think it's very good for any of us to have to be reminded all day and all night about what the future may have in store for us. Besides, if they aren't being well cared for, what do I have to look forward to if that happens to me?. . . It's a big burden for us to make sure they (the impaired) get to meals and find their rooms and there just aren't enough staff to manage."

The Institute of Gerontology has long advocated the designing of treatment environments for persons of similar needs, abilities, and deficits (Coons, 1983), and, through research, has documented the effectiveness of such a policy. It is essential, however, to view the grouping of persons according to capacity as an opportunity to design the physical environment, the activities, and the staff approaches in ways that are appropriate and can best accommodate the needs of special populations. Grouping alone is not sufficient; it is only the first step in the development of the therapeutic milieu.

Small Versus Large

The Wesley Hall project has documented that the size of the treatment setting for cognitively impaired persons is of utmost importance, both in terms of physical space and the number of residents and staff. Eight to twelve residents with an appropriate number of staff can provide a far more therapeutic and nonstressful environment than an area housing 20 to 30 persons, with a relative increase of staff. The number of persons alone becomes overwhelming.

Too large a space seems to be confusing and disorienting for people with dementia. A warm, cozy home-like environment is much easier to create for eight to twelve people than for a larger number. Staff and residents are able to develop a much closer relationship, and shared group activities are more easily organized and managed within a smaller setting.

Social/Residential Care Model Versus the Medical Model

One of the dilemmas in our current health care system is that it is not prepared to care for a rapidly growing population of elderly persons with dementia who are physically active and well. This group does not need the expensive skilled nursing care designed primarily for the physically impaired. Additionally, people with Alzheimer's disease do not require or respond well to the structure and design of the traditional nursing home. THey are strongly resistive to the rigid schedules which are often adamantly adhered to -- such as bath, meal, and bedtime routines -- by overworked staff. The result is the anger and combativeness attributed to the stereotypical picture of the Alzheimer's victim.

The findings of the study reported on here give strong evidence of the benefits of the social/residential model in providing therapeutic milieus for persons with dementia. Characteristics of the model will be described throughout this paper.

Wesley Hall: A Special Living Area for Persons with Dementia

In December, 1983, the investigators began the demonstration project entitled Wesley Hall. Developed as part of a retirement home, it was designed to determine the effectiveness of carefully planned social and environmental interventions in providing an improved quality of life for persons with Alzheimer's disease and in reducing many of the difficult behaviors considered characteristic of the disease.

The Chelsea United Methodist Retirement Home is located in the small town of Chelsea, Michigan. The retirement home, with 159 residents, is part of a 26-acre campus which also includes separate apartments for independent living and a 110-bed facility for intermediate and skilled nursing care. Residents of the retirement home are expected to be capable, with a minimum of assistance, of managing basic activities of daily living.

In 1983 the retirement home was facing a crisis situation typical of many such facilities throughout the country. As its population aged, many had become increasingly impaired and, according to estimates of the administrator, approximately 10 percent were suffering from severe memory loss. They were ambulatory and relatively well physically and were thus considered inappropriate candidates for the nursing area. They were no longer able to manage, however, in the large and widely separated areas of the retirement home. Some were unable to locate the central dining room, others were incontinent in their futile effort to find their hall's bathroom. As they drifted in and out of other residents' rooms, aimless in their search for areas they could not indentify, they became the constant targets of the anger and resentment of the alert residents. They soon acquired the labels of the "crazies" and the "seniles" and, with the constant verbal abuse from the more mentally able residents, they became increasingly agitated and fearful. Some seldom left their rooms. It was an equally difficult time for alert persons who attempted to help them or who were disturbed both day and night by their wandering.

When the home's administration approached the investigators for assistance, a decision was reached to establish a special living area, to be called

Wesley Hall, that could be redesigned to accommodate the deficits and, at the same time, encourage the use of the remaining skills and abilities of this vulnerable group. Lawton (1980) notes that as an individual's "competence decreases, external environmental factors become more and more important determinants of behavior and affect."

The Wesley Hall project was designed as a two-year experimental demonstration study. It was expected that there would be a constant testing and evaluation of new approaches, activities, and systems that could be used successfully with persons who were severely impaired. Staff were encouraged to question traditional patterns of communication and methods of working with impaired persons and to develop close, supportive relationships with residents. Since the eleven residents (9 women and 2 men) selected for the study were not in need of extensive medical care, staff had fewer responsibilities for "treatment" and could spend time with residents in more "social" roles.

In planning for Wesley Hall, the investigators studied the factors that could potentially influence the way residents responded and could have strong impact on the quality of life. It was recognized that drastic changes would need to be made in the physical environment and in the way staff related to residents.

The Physical Environment

Wesley Hall is located on the top (fourth) floor of one wing in the retirement home. Its long hall and lack of direct access to the outdoors made it far from ideal, but this space was chosen because it had two bathrooms (one for men, one for women). The area was also separated from the rest of the home and did not serve as a major thoroughfare to other wings. At one end of the hall a large public space was converted into a kitchen, and a dining/living room area. A small den at the other end of the hall provided residents with a secluded space for napping or just being alone. Figure 1 illustrates the arrangement of the eleven private bedrooms opening onto the long hallway.

Because the retirement home was a very old building with poor lighting, no orientation cues, glossy tile floors, outdated plumbing and drab decor, Wesley Hall was completely renovated in preparation for the project. Many of the environmental design decisions were based on research that has been done on designing environments for elderly people (Hiatt, 1979, 1982; Lawton, 1981; Pastalan, 1979). The Wesley Hall project rested on the principle that both the social and physical environments can be significant factors in the care and treatment of dementia victims. Hence, the environment on Wesley Hall was designed and programmed to help residents continue to function optimally and to support positive behaviors. In order for the residents to continue the tasks of everyday life, such as washing and drying dishes or baking, it was imperative that modifications be made in the physical environment.

Wesley Hall became a warm, restful and, at the same time, stimulating setting where residents could have easy access to all areas. Ceilings were lowered and lighting was doubled; the living room, den and dining room areas were furnished with homelike furniture. A small kitchen became the hub of much activity. Cupboard drawers and doors were clearly labeled, indicating

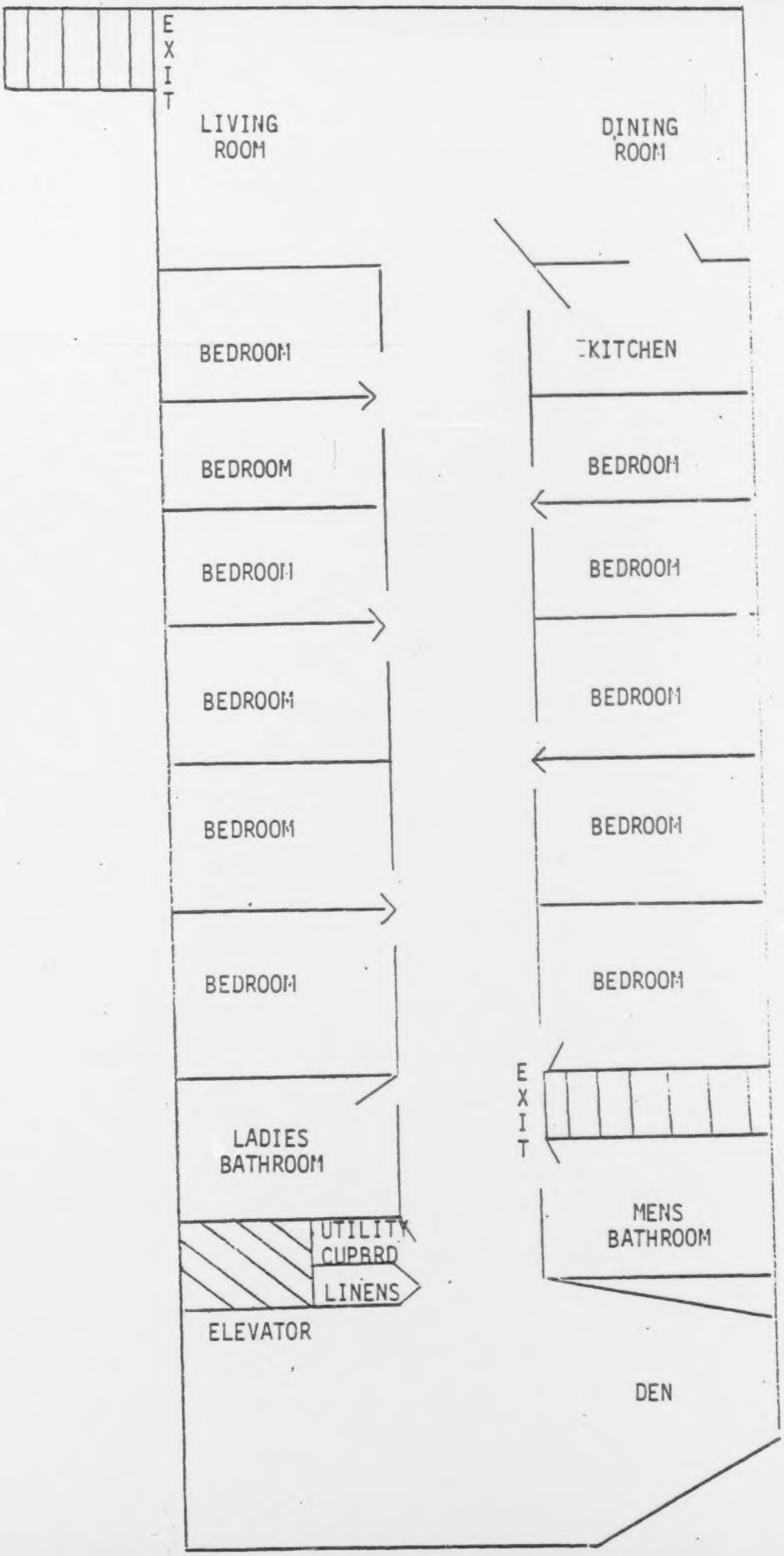
EXIT
LIVING ROOM
DINING ROOM
BEDROOM
KITCHEN
BEDROOM
BEDROOM
BEDROOM
BEDROOM
BEDROOM
BEDROOM
BEDROOM
BEDROOM
BEDROOM
BEDROOM
EXIT
LADIES BATHROOM
UTILITY CUPBRD
LINENS
ELEVATOR
MENS BATHROOM
DEN

FIGURE 1: FLOOR PLAN AT WESLEY HALL

where cutlery, dishes and baking utensils were stored. A special switch and timer were attached to the kitchen stove to ensure that it would be turned on only when staff were in the immediate area to supervise cooking activities.

The staff desk and medication cupboard were located in one corner of the kitchen. The availability of a separate space for staff is controversial. Wesley Hall was designed on the premise that setting aside a separate space for a staff office reinforces the hierarchy which traditionally exists between staff and residents.

Primary colors -- reds, kelly greens, and yellows -- were used wherever possible to provide stimulus and to help residents with visual problems. Wallpaper was used to provide a warm, non-institutional appearance. In the bathrooms, colored toilets, bathtub and lavatories were sharply contrasted with the floor and wall colors (Hiatt, 1981). This helped residents to delineate boundaries and to highlight spaces. The tiles used in the bathroom have a matte finish. A bathtub and shower with a molded seat comprise the bathing area and is separated from the toilets by a swing door.

Gradually, as needs became apparent, signs were installed to direct residents to specific areas, to call attention to the contributions each resident made to the daily life of the area, and to help maintain personal identification. A number of photographs illustrating residents' involvement in various activities were greatly enlarged and hung in the hall to form a gallery. Residents frequently stopped to observe and call attention to these pictures. Because of the enlargements, some were able to recognize themselves, and occasionally they could say a word to two about the activities captured in the photographs. This provided residents and staff with opportunities to reminisce about the good times they had together.

Each residents' room was individual and personal. Families brought in furnishings from their relatives' homes and added accessories which reflected their earlier lives and interests.

Personal possessions were not stolen as some staff feared; and, after rooms were clearly labeled, only M. had a short period when she wandered in and out of others' rooms. A number of interventions were tested including signs posted on the doors of her favorite rooms reading "Do not enter. This room belongs to ______." This helped to deter M., but on occasion staff found it essential to calmly point out that she was in the wrong room and that they would help her find her own. Eventually even the signs were no longer needed. To help residents identify their own rooms, a wall plaque with name and picture were placed to the left of each person's door and a special decoration attached to the door itself.

The warmth of Wesley Hall with its many personalized features seemed to provide residents with a sense of identity and security.

Residents

The selection criteria included the following: the Wesley Hall resident was (a) ambulatory; (b) able to feed him/herself; (c) having problems with severe memory loss; (d) not in need of more than a limited amount of medical care; (e) able to manage at least some self-care with the assistance of staff; (f) able to follow instructions related to very simple tasks.

One of the eleven residents had a diagnosis of dementia secondary to viral encephalitis. For the remaining residents, the physician's presumed diagnoses were Alzheimer's disease or multi-infarct dementia. Several of the residents were no longer able to recognize relatives when they visited, and most were unable to call close relatives by name. The Mental Status Questionnaire (MSQ) (Kahn et al., 1960) was administered to all residents. The scores, showing severity of brain syndrome, rates 0-2 errors as none or minimal impairment, 3-8 errors as moderate, and 9-10 errors as severe (Kane and Kane, 1981). Since the opening of Wesley Hall, residents have consistently scored in the range of 8-10 errors or "don't know" answers, placing them in or bordering on the category of the severely impaired.

Staff Training

Most of the staff for the project area were selected from interested persons who were already employed in the home. Everyone to be involved--nursing staff, residential assistants, and housekeepers -- were given a month-long training program prior to the opening of the area. A variety of training techniques and materials based on earlier Institute research and tested over a number of years in continuing education seminars were used to prepare staff for the new project (Misplon and Metzelaar, 1980). But parts of the training, too, were experimental. While it included information on dementia and issues related to medical care, emphasis was placed on empathy training and staff's learning to identify the strengths and needs of persons with severe memory loss. Special exercises were designed to help staff better understand their style of communication and how this might affect residents. For example, experimental training exercises were designed to enable staff to be more sensitive to situations in which they were controlling or condescending. It was stressed throughout that dementia victims have little or no control over their behaviors, and that it becomes the responsibility of staff to examine their own approaches in order to help reduce some of the behaviors induced by stress. In other words, the object was to "avoid" rather than "manage" difficult behaviors.

Part of the training included spending time on a one-to-one basis with residents selected to move to Wesley Hall. This resulted in staff viewing residents in very different ways, and residents themselves began to change even before moving to Wesley Hall as a result of the attention they were receiving from staff. One man whom staff at first feared because of his combativeness became one of the most popular of the selected residents. In an early training session he had been described as angry, hostile, and impossible to manage. Several weeks later this same man was attributed with having social graces and a marvelous sense of humor.

As in earlier Institute projects, the training emphasized the "well" aspects of the individual, a point of view which described the older person in terms of capacities and potential rather than diagnoses and problem behaviors. Staff were taught how to recognize the remaining skills and capacities and to build upon those strengths, while at the same time, accepting the individual's deficits and behaviors. As a result, Wesley Hall staff developed positive attitudes toward people with severe cognitive impairment.

Staffing Pattern

During the second year of the project, Wesley Hall had a full-time coordinator, one full-time and a half-time resident assistant (called "aides" in the retirement and nursing homes) on day and afternoon shifts, one-full time resident assistant on the midnight shift, and a part-time housekeeper. Medications and other medical care were administered by the nursing staff from the retirement home. The staff/resident ratio was lower when Wesley Hall opened, but it was soon discovered that residents needed greater assistance with self-care activities, for example, than the fewer number of staff could provide. A highly skilled and dynamic coordinator was seen as a critical component in the success of Wesley Hall.

The primary physician, who was the medical director of the home, did a diagnostic workup on each resident, did weekly evaluations and prescribed medical treatment. A psychiatrist who specialized in treating some of the psychiatric problems associated with dementia served as a consultant in special situations. On recommendation of the physician, several residents were admitted to a geriatric unit in a psychiatric hospital for evaluation, and this was followed by a ten-day observational period in the unit during which time the physician evaluated the pharmacological interventions.

Life on Wesley Hall

In designing therapeutic environments, Institute of Gerontology research has emphasized the need for the availability of normal social roles so that residents can continue to function and be involved in activities which had meaning to them in their earlier lives. The theory supports the idea that "roles prescribe the patterns of behavior which are socially acceptable for each position or function in a group or society. If, for example, the only available role is 'frail sick patient,' the individual will conform to the expectations embodied in that role. If, however, a number of normal nonsick social roles, such as friend, citizen, consumer, worker, or user of leisure time, are available and the individual is encouraged to choose freely among them, his or her behavior will be varied and far more therapeutic in its effects, than when it is prescribed by the sick role. These roles enable even the very frail to respond and to function in an environment which is nurturing and enabling" (Coons, 1983). With this concept in mind, the daily living on Wesley Hall was designed specifically to reinstate, to the extent possible, the roles of homemaker, family member, volunteer, and friend.

In the role of homemaker, residents were involved in setting the tables, washing and drying dishes, baking muffins and cookies, making home-made ice cream, folding towels, and, with the guidance of a housekeeper, assisting in bed making, vacuuming and dusting. In the role of volunteer, most of the residents were able to participate in carefully selected service projects. They successfully completed a variety of projects for the American Red Cross, such as folding flyers or stamping envelopes. Another favorite service activity was making garnishes for the retirement home's central dining room. Activities such as family potlucks were organized to encourage family involvement and to strengthen and reinforce the resident's role as family member (Coons and Weaverdyck, 1986).

The Tone and Spirit on Wesley Hall

One of the goals of Institute staff in designing the milieu for Wesley Hall residents was to try to achieve a stress-free setting. Questions arose about how a rich environment, full of opportunities for involvement, could be offered without increasing the level of stress. The residents on Wesley Hall responded well to the stimulating environment. Stress was reduced by carefully tailoring each activity to what residents could manage successfully and by giving everyone the choice of accepting or rejecting participation at any time. The contrast between the behaviors of residents when they were living in the larger retirement home where their days were spent in restless wandering or sitting alone in their room and their behaviors on Wesley Hall suggests that the absence of opportunities creates or increases the stress.

The project has given many insights into ways of reducing stress. There needs to be a degree of structure and consistency in the environment and daily practices, but the results of the study have also shown that rigid routines and inflexible schedules are non-therapeutic and stress producing. The relaxed and flexible approach to carrying out the daily routines began with breakfast. It was available between 7:00 and 10:30 a.m. to accommodate the early risers and the late sleepers. The bath schedule, too, was flexible in order to avoid coercion and to enable staff to respond to favorable moods of residents. Many of the activities were spontaneous and unplanned. The singing of old songs was a popular pastime and often accompanied such tasks as towel folding or doing service projects. Staff usually initiated the singing but several residents were able to begin another song which was quickly picked up by others. Most of the residents were able to sing the words to entire songs even when they were unable to remember participating in the activity a few minutes later.

Staff Approaches

Institute staff are convinced that the key to providing a therapeutic milieu which will enable the impaired residents to respond in positive, "well" ways is through new staff approaches. Coercion and control are inappropriate and can create such havoc that the entire group will become affected and respond in angry and combative ways. No physical restraints were used on Wesley Hall, and psychotropic drugs were kept to a minimum and closely monitored. If they caused negative effects, such as drowsiness, the physician either reduced the dosage or dropped or changed the medication. Even when staff found an effective way to approach a resident, it was not necessarily suitable on another occasion. This required staff to have a wide variety of approaches and to know residents so well that they were able to sense the individual mood of the moment and respond accordingly. This negated the use of a uniform approach with all residents, a practice followed in many traditional settings, for each person had individual needs and personality. A number of approaches are described below.

Diversion often helped to reduce stress. Occasionally a resident became agitated when there were a number of people around or a lot of activity. Staff would then approach the resident and say quietly, "Let's walk down to the kitchen and have some fruit juice together." At times a resident would begin pacing in search of a relative whom she expected to take her home. Staff would walk with her and remind her that her son had been there for a visit recently and they had gone out for lunch. These and other diversions shifted the focus of attention and gave residents opportunities to relax.

On occasions when staff found themselves unsuccessful when they approached someone, they would withdraw and return later. A quiet leave taking with a promise to return expresses caring and interest of staff and gives reassurance to the resident. Staff find that persons with dementia become agitated when they are unable to understand what is expected of them. One of the men became very angry at night when staff attempted to help him undress for bed. They would often withdraw and return a little later. Sometimes it required several attempts before he seemed to grasp what they were asking him to do.

Touch and a sympathetic approach was often effective. If someone became quite agitated and began to pace, staff found it helped to put an arm around a shoulder and say quietly, "Let's walk together for a while and see what's happening down in the den."

Staff also found themselves reinterpreting some behavior as normal and therefore not in need of change. For example, residents sometimes became angry when staff seemed authoritarian. When staff could accept that as a reasonable reaction and similar to how they, themselves, might respond in the same situation, the behavior was identified as legitimate. It, therefore, became the obligation of staff, not the resident, to change behaviors.

One of the keys to the success of Wesley Hall was the humor and lighted-hearted style of staff. The style of humor varied from subtle, gentle kidding to occasional clowning absurdities. Even the most impaired persons on Wesley Hall were able to respond to humor. Some staff felt very uncomfortable with this light, almost frivolous approach with the impaired elderly, but the outcomes demonstrated the therapeutic value of humor and laughter. The 36-Hour Day (Mace and Rabins, 1981) speaks of the presence of human emotions in persons with dementia: "A dementing illness does not suddenly end a person's capacity to experience love or joy, nor does it end her ability to laugh." The informal, relaxed atmosphere created at Wesley Hall allowed for spontaneous, natural and cheerful experiences to take place, much as they would in a non-institutional setting. Because residents knew it was legitimate and safe, they at times initiated humor, kidding staff about something they were doing or joking about some incident of the moment. Nahemow (1986) suggests that if humor and fun could be introduced in care settings, they would increase the responses of residents, which in turn would create a more effective, therapeutic, and complex environment, largely influenced by the older people themselves.

OUTCOMES

Five of the original residents still lived on Wesley Hall by the end of the two-year project, but each required an increasing amount of help from staff in completing tasks. Early screening methods were far less elaborate than those that were eventually designed, and as a result, two of the first eleven selected were much more severely impaired than the simpler screening methods showed. It was clear from this experience that it was essential that the screening methods differentiate between persons who had excess disabilities, and, thus, could benefit and improve as a result of the interventions on Wesley Hall and those who were so ill that they needed greater care than was available there. It quickly became apparent that the expectations of the area were far too great for the two of them and that they needed much more nursing care than Wesley Hall staff could provide. They and other residents who later became physically ill and in need of intensive care were moved to the nursing area of the home or to other nursing homes.

Residents made a variety of gains from time to time, sometimes for short periods. There were three major areas of gain, however, that remained consistent and could be described in terms of specific interventions. There was a reduction in incontinence, in night wandering, and in combativeness. There was also a decided difference in the appearance of residents from when they were living in the larger retirement home. Most looked well, so much so that visitors found it difficult to believe, at first, that residents were really victims of dementia. This change in appearance was difficult to describe in terms of interventions and even more difficult to measure. However, increased self-esteem seemed to accompany these positive changes.

Incontinence

Hodge (1984) speaks of the complexity of dealing with incontinence in persons with dementia. He stresses the need in designing programs for incontinent persons "for comprehensive behavioral analysis, taking into account all the various possibilities, both organismic and environmental which may interact to lead to the specific behavior under review." He lists the following as potential problems for persons with dementia:

1. Inability to recognize need.
2. Inability to find toilet.
3. Too slow to get there.
4. Inability to recognize toilet.
5. Inability to undress appropriately.
6. Apathy.
7. Incontinence maintained by contingent staff attention.
8. Medical problems.

Staff of the Institute of Gerontology worked closely with The University of Michigan Incontinence Clinic in developing appropriate interventions. An incontinence check of residents by the Clinic prior to their move to the Wesley Hall area revealed that four of the eleven residents were incontinent. The Clinic staff also examined all residents shortly after they moved to the area to determine if any had urinary tract infections for which treatment was needed. Individualized toileting schedules were established for the four persons who were incontinent. The Clinic staff also recommended that there be a decided increase in liquid intake, both to provide the body with essential liquids and also to give bladders the quantity of liquid required to make persons aware of the need to urinate.

There were a number of problems that had to be dealt with. There were two bathrooms off the hallway -- one for men and one for women. The lack of toilets in individual resident rooms meant that several of them were quite a distance from the bathrooms. The four persons who had been incontinent before the move were placed nearest to them. Some had difficulty locating the bathrooms. To make them immediately visible from any place in the hall, small hrightly colored awnings (red for women and blue for men) were placed over the doors. Signs were posted on the doors to add additional cues. Staff became immediately aware of the importance of terminology when the sign "WOMEN" on the one door brought puzzling comments. Several were heard to question in their own ways what went on behind that door. A new sign "LADIES BATHROOM" quickly replaced the other and clarified the issue.

Several other residents were able to recognize the urge to urinate, but they could not proceed without help from staff. As staff became sensitive to the nonverbal cues of individual residents they were able to avoid incontinence. One man, for example, at times would get up in the middle of a meal, begin tugging at the zipper on his pants, and at the same time start swearing at anyone near him. Staff soon learned that what he needed was some assistance in locating the bathroom. His language skills were so impaired that he was no longer able to communicate his need to staff. One of the women became delusioned and agitated when her bowels became impacted. Staff developed a set of interventions to respond to her problem, and measures were taken to prevent impactions.

During December 1983 and January 1984, the assistant on the midnight shift reported frequent incidents of urinary incontinence for four of the residents and occasional accidents for two others. Four were placed on toileting schedules varying from 2 to 3-1/2 hour intervals, and several others were reminded at times if they had periods when they had difficulty getting up on their own initiative. As mentioned earlier several were able to get up in time but needed help in locating the bathroom.

By March 1984 the toileting schedule was in place after testing the effectiveness of the time intervals. Occasionally there were incidents of incontinence but the frequency was greatly reduced. Excerpts from the March 8 log by the resident assistant reported the following:

12:00 a.m. - D. and E. went to the bathroom with my help.
2:00 a.m. - D., E. and J. to the bathroom with my help.
3:30 a.m. - D. to the bathroom on his own.
4:00 a.m. - E. to the bathroom with my help.
5:00 a.m. - D. to the bathroom on his own.
6:00 a.m. - E. to the bathroom with my help.
No incontinence tonight!

As with other tested interventions, those designed to reduce incontinence had impact on behaviors, but none could be said to be effective with everyone all of the time. The objectives were to reduce the discomfort and indignities to individuals to the extent possible.

Wandering and Sundowning

The wandering behavior for the first few months on Wesley Hall did not come as a surprise. Most of the residents had been described by staff as being both day and night wanderers while they were in the large retirement home.

Day time wandering usually followed the patterns of going back and forth through the hallway, in and out of the kitchen, and searching for their rooms. During the first several months of the project, a resident occasionally left the area by elevator without the knowledge of staff. This was frightening for both staff and the resident involved at the time, but locking the area was not considered as a possible solution. The two exit doors, one from the living room and one from the hall, had been painted to match the surrounding walls. The camouflage was evidently effective, becuase no one attempted to open them. For a short period of time the elevator button was covered by a needlepoint square reading "Wesley Hall." This proved helpful, and at the same time staff became more carefully alert to residents who approached the elevator, diverting them to another part of the area. With these precautions and as residents became more comfortable in the area, the problem largely disappeared. Most of the restlessness and agitation appeared at twilight immediately after the evening meal. At this time of the evening, some residents searched anxiously for relatives to take them home. Night also became an active time. Some persons were up for several hours at night, unable to get to sleep.

A number of interventions were tested to determine ways to help residents relax. As residents became comfortable and more familiar with the area, day time wandering was greatly reduced. In fact, two of the most active wanderers claimed a love seat in the living room which had full view of the hallway. This enabled them to observe any action in the hall, and it seem to become a substitute for their earlier wandering.

Snyder et al. (1978) in their article on wandering give a number of legitimate reasons for residents to wander. They suggest that "placid wanderers may be bored or repeating a real or imagined activity. . . Agitated wanderers may be releasing their tension and frustration through motor activity. . . The 'happy' wanderer may be coping by exercising or just exploring." They concluded that the acceptance of wandering as legitimate, in itself, reduced "the prevalence of the 'problem' wandering behavior."

The resident assistant on the night shift was prepared for much activity at night, and, for several months, the period between 11 p.m. and 7 a.m. was almost as active as day time. Interventions, planned in training, were to include a variety of activities and approaches which might help residents relax. In other words, wandering was acceptable.

The period after the evening meal was the most difficult to resolve. Thinking that the darkness might be the cause of the agitation, staff pulled down window shades to block out the outdoor darkness. This as well as the diversional approach mentioned earlier were helpful. One of the most effective interventions was the implementation of a variety of activities involving most of the residents. Gradually this evening period became the most active time of the day. Residents became quite involved to the point that most went to bed at 10:00 or 11:00, tired, relaxed, and diverted from the problems that seemed to cause them so much distress.

The staff log recorded some of the contrasts in sundowning during the first several months and those of the later months after staff had attempted a variety of interventions. Excerpts from the log recorded on December 30, 1983, the first month of the project, by the resident assistant on the night shift illustrated that residents were still continuing their habits of restless wandering.

> 12:30: R. came to the dining room with a washcloth. She was rubbing the back of her left leg and seemed to have some discomfort. I put an ice pack on it for a while and she said she felt better. R. went back to bed and I told her to let me know if it started hurting her and she couldn't get to sleep.
>
> 1:00: E. came out fully dressed. I told her the time and she went back to bed.
>
> 1:15: J. was up wandering around her room. I took her to the bathroom and then tucked her back in bed.
>
> 1:35: R. got up again and said she couldn't sleep. We had hot cocoa together, and she helped me make some

muffins for breakfast. She did a few dishes and then went back to bed about 2:35.

2:40: M. was sitting on her bed, about to get up. She was still in her nightgown. I helped her get back in bed, covered her up, and she went to sleep.

3:45: T. came down the hall fully dressed and she had made her bed. I took her to her room and showed her the clock. She told me the correct time and was willing for me to help her get undressed and back to bed.

5:05: L. was up and getting dressed in her room. I told her how early it was, but she still wanted to stay up.

5:15: T. was standing at her door and clapping her hands, a habit she has started recently when she wants attention. She seems to resent it when I'm helping others. I told her to come to the dining room if she wanted something and didn't see me.

5:20: L. came to the dining room and wanted something to eat. She had several pieces of cinnamon bread and two cups of coffee. R. came in shortly after and sat down with L. and had some breakfast, then both went back to their rooms.

5:45: T. came down to the dining room to find me. She wanted to know if it was time to get up. I feel this was an important step for her and me. Much better than clapping her hands and becoming so angry.

By the middle of March 1984, notes such as "Quiet tonight - no problems," began to appear occasionally in the log. Staff efforts on those nights were devoted almost entirely to carrying out the incontinence schedule.

By mid-May only T. was having difficulty sleeping, sometimes getting up eight or more times either to go to the bathroom or to check on the time. A number of interventions were tested. The resident assistant sat with her when she seemed very restless and sometimes rubbed her back to help her relax. When she left the room she would reassure T. that she would check in frequently to see how she was doing. At other times staff would involve her in making cookies or muffins or preparing vegetables for snacks. She enjoyed these activities, and they seemed to help her relax. Gradually the frequency of her restless periods was greatly reduced.

Anger and Combativeness

Bursts of anger and combativeness are often some of the most difficult behaviors for staff to deal with. Often they occur unexpectedly when the staff person may be the least prepared to respond. Mace and Rabins (1981) emphasize the importance of accepting "that these behaviors are not just stubbornness or nastiness but a response the person with a dementing illness cannot help." After the Wesley Hall area opened, weekly staff problem solving sessions often focused on ways to reduce the amount of explosive anger and on considerations of what might be triggering the incidents.

In one session, a resident assistant reported on an experience she had had several days before. She had gone to the room of one of the men to suggest it was time for him to go to the bathroom. He became furious and began screaming profanity at her. She said calmly but firmly, "I am trying to help you, and I don't like to have you talk that way to me." She went on to say, "He stopped and looked at me in the most crestfallen way and said, 'I don't know any other words,' and then he walked along with me with no more swearing. I felt so bad; I gave him a big hug." This story and others helped staff to recognize the powerlessness of persons with dementia and the desperation they must feel at times.

A number of approaches and interventions helped to reduce the frequency and intensity of the anger. Staff gradually adopted a relaxed and unhurried style. They became sensitive to each individual's moods, and they could often avoid a possible explosive reaction by diversion or by chatting in a light and bantering manner. Often times it became essential for staff to withdraw from the situation and return later.

Several residents resisted taking baths and became angry, often striking out at staff; so a variety of approaches were tested. One staff person found it helpful to sit down with Mrs. E., chat a while, then suggest they walk down the hall together. The bath water had been drawn shortly before, and on reaching the bathroom, the staff person would say, "Let's go into the bathroom while we are here." Once inside she would say, "Look at that good, warm bath! Let me help you take a bath while we're here." This approach was not always successful, but it was far more successful than coercion or a more direct approach, and much less stressful.

At times staff would say to a resistive person, "There are some delicious chocolate chip cookies in the kitchen. Let's go down to the bathroom and I'll help you take a bath and then you and I will snitch some of those cookies and have a party -- just the two of us."

One innovative staff person had had a totally unsuccessful morning in getting G. to take a bath. He became verbally abusive and she withdrew. Later she sat down with him and asked, "If you had your choice, what would you like to eat while you're taking your bath?" He replied promptly, "A dish of ice cream." She responded to this immediately saying, "When you get into the tub I'll come back to the kitchen and get you that dish of ice cream, and you can have it while you're taking a bath." He chuckled and said, "'They' won't like that." The resident assistant said quickly, "We'll never tell 'them.'" This conspiracy appealed to G., and the bath combined with eating of the ice cream proceeded with no further problems.

While no single approach was necessarily successful every time, some approaches were consistently unsuccessful. In any case, staff needed a repertoire of potentially successful approaches from which to choose. This required imagination and a willingness to try positive, though often non-traditional, ways of helping residents through difficult situations in an effort to enable them to live with a minimum of stress.

Improved Personal Appearance

There was a change in the appearance of residents who, before coming to the area, looked confused, ill, out of touch, and depressed. Gradually they became more alert, well looking and involved. This led to much speculation by staff about what specific interventions had made the difference.

Special efforts were made to help residents be well groomed. Staff worked with families to provide a variety of attractive clothing. Good hair and nail care was considered essential as were bathing and dental care. Women wore make up and jewelry; men were helped to shave regularly. These are all essentials for anyone in feeling well groomed.

The changes went beyond grooming, however. Except for an occasional nap, residents appeared alert and aware of their surroundings. Personality blossomed. They smiled or laughed easily and often. They were quick to establish eye contact with anyone approaching them.

Certainly their constant interchange with staff must have been a major factor. The shared activities provided occasions for conversation or light banter. When staff was giving a resident help in any self-care activities they explained the steps involved, encouraged, reassured, complimented and reminisced or laughed together about any funny thing that might have occurred.

Group activities also provided occasions for chatting and levity. The interaction recorded among four residents and two staff sitting around a table folding towels perhaps can illustrate the light relaxed tone staff tried to maintain.

This activity began with suggestions from one of the staff members about ways to fold towels. Residents began the activity, concentrating intently on the task. As the folding continued there were comments from staff about the colors of the towels, and questions about residents' favorite colors to which two responded. At one point a resident said with a chuckle to the staff person sitting next to her, "That's your elbow in my way." Laughter from everyone and staff responded, "I'd better keep my distance." Staff a little later suggested that they whistle while they worked; she started a song and three of the residents joined in. In between songs, residents made such comments as, "My brother could whistle all around me" and "Someone is out of tune." Throughout the activity there was frequent laughter and occasional comments or a few words from three of the four residents. This constant stimulation in a relaxed and undemanding milieu seemed to be effective for even the most impaired residents.

PROBLEMS IN DEVELOPING A NON-TRADITIONAL MODEL OF CARE

The role of staff on Wesley Hall differed greatly from that in the traditional setting. Pre-project instruction focused on their role as enabler as opposed to caretaker. They were expected to help residents continue in as many self-care activities as possible. This required time and patience, neither of which is available in many treatment settings. High priority was placed on staff communication with residents, and it was pointed out that any shared activities would give staff occasions for chatting with residents. It was also stressed that touch played an important part as a means of communication with persons with dementia. On the whole, staff welcomed this new approach and soon came to recognize the values for both residents and staff.

Lawton (1980) discusses the problems some staff have, however, with such an intimate approach. In describing one facility studied, he stated that staff "were made uncomfortable by such transgressions into their 'personal bubble.' They withdrew physically whenever possible. When residents' personal-care needs forced staff to touch residents or interact at very close distances psychological distancing mechanisms occurred such as looking beyond the resident, arching the body away, handling the resident roughly, or conversing with someone other than the resident being assisted."

In programs such as Wesley Hall, the demands on staff are great and unending. They cannot resort to the separation from residents and the impersonal and aloof stance which serve as protections in some traditional settings. The possibilities of burnout must, therefore, be faced and measures taken to reduce stress on staff. To address the problem, some programs have adopted a policy of rotating staff at set periods. This can present problems for residents. The changes in personnel require that residents become familiar with one group of staff only to be presented with a new group of faces in a relatively short period of time. This problem can be somewhat alleviated by staggering the rotation of staff and by establishing a close working relationship among the groups that are rotating. Staff rotating presents other problems that made such a policy inappropriate for the Wesley Hall project. It is difficult for a stable, consistent, and dynamic program to be implemented when staff view their jobs as temporary. A stable staff is essential also in building a cohesive team who learn to work together in solving problems and in providing the support to each other needed to reduce the potential of burnout.

One measure taken at Wesley Hall to avert staff burnout was to use weekly staff meetings as problem solving and training sessions. This enabled staff to present specific difficulties they were having and develop a plan of action for the following week. The next meeting gave them an opportunity to report on the success or failure of the planned interventions. In addition to the weekly meeting, the director of the project met with each staff person individually to give additional support and help.

One of the things which staff described as being particularly helpful was the understanding that the project was designed to learn more about how to provide a better quality of life for persons with dementia, and that answers would come only from their trying new things. It was safe for them to try something and fail, because knowledge would come from the failure as well as from the successes. The daily log of their experiences which they were asked to keep testified to how comfortable they felt in the situation. Their own evaluations of the results included such expressions as, "It was a great idea, but it bombed. Maybe I needed to do it in a different way"; "It worked" and later, "What worked Tuesday caused trouble today," "I am just having no success with E."

A number of interventions were introduced in an effort to erase features of treatment settings which are constant reminders of sickness and institutional living. The intercom unit in the area was disconnected. Voices coming from an unknown source can be disturbing and confusing to persons with dementia, as well as a frequent reminder that they are living in an institution.

Wesley Hall had no nursing station; case notes were made at a small desk in the kitchen and the only locked space was a small cupboard where records and medications were stored. In a further effort to create a home like environment, staff wore street clothes. Many of these changes, symbols of the separation between staff and residents and the controlling position of staff, are difficult to implement in very traditional settings without strong administrative leadership supporting the changes.

Many of the opportunities to be introduced in Wesley Hall required alterations in the physical environment which had the potential of conflicting with certain state requirements. In anticipation of this, Institute staff met with the inspection officer of the State Department of Public Health to explain the objectives of the project and to seek permission for the installation of a small kitchen, acceptable as a "learning resources center," and for residents to wash and dry the dishes used at meals. Both of these requests were granted. The fire marshall was consulted to ensure that the new furniture arrangement would meet safety regulations.

A series of meetings with the employees' union in the home prior to the opening of the area was especially crucial to explain why staff were taking new roles and why residents would be involved in many tasks ordinarily handled by staff in other parts of the home. The union was cooperative and supportive of the plans.

Consulting with persons who are expected to maintain specific regulations or standards prior to the implementation of a project is almost imperative.

It can avoid many problems later on when the changes could be interpreted as deliberately ignoring the various requirements that are part of the regulatory system.

Wesley Hall was a section of the old age home rather than the nursing home in the Chelsea complex. This presented problems for several families, for there was no mechanism available for reimbursement for an intermediate level of care in the State of Michigan. Wesley Hall was not designed to be a private pay area, and, with the special efforts of the home's administrator, two families were able to get supplemental support. After the State Department of Public Health granted the request, supplemental reimbursement was issued by the State Department of Social Services. It is unfortunate that some states have no systems for reimbursement of such a setting as Wesley Hall, because the costs are less than nursing home care. At the time of the completion of the project, daily costs to residents of the old age home unit were $29.70; Wesley Hall residents paid $42.65 a day; and the nursing home section cost $60.00 per day.

PERIOD OF TRANSITION

The Institute of Gerontology's role in the project terminated in December 1985. At that point the staff of the home assumed full responsibility for the operation of Wesley Hall. The administration of the home has expressed strong commitment to the continuation of the experimental area, and are, in fact, considering the establishment of two other similar areas in the Chelsea home and one in a sister facility in Detroit.

During the transition period, in an effort to keep to a minimum the problems inherent in such a changeover, the Institute offered another series of training and problem solving sessions for the staff. Institute staff will continue to serve as consultants to the new director of the unit for an indefinite period of time.

CONCLUSION

The memory loss, disorientation, combativeness, and wandering behavior considered characteristic of many forms of dementia tend to confound every aspect of medical and nursing care. In spite of this, there has been very little careful study and documentation of daily care techniques which could maximize the quality of life for these individuals. To this point, they present only an overwhelming and inexplicable enigma to persons attempting to treat or care for them.

Baro** (1983) predicts that it will be at least the year 2000 before biomedical research will be able to identify the causes of and appropriate clinical treatment for Alzheimer's disease. Pending major breakthroughs in cellular physiotherapy, he urges that "most health care systems need to markedly alter the efficiency and effectiveness of their therapeutic efforts directed toward this special and vulnerable population."

The residents on Wesley Hall have demonstrated that persons with dementia can respond and benefit from a therapeutic milieu which is sensitive to their

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needs and responsive to their moods. The project gave convincing evidence that staff can learn to work effectively and gain great satisfaction in providing a positive and supportive quality of life for impaired persons.

It is imperative that policy makers and health care specialists take a fresh, new look at what is possible. Dementia is devastating in itself; families and the victims need to have available to them models of care which ameliorate, not deepen, the devastation.

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THE SENIOR RESPITE CARE PROGRAM

PLANNING

I was hired 12/4/83 to implement a new program in the Portland, Oregon area, a respite care program.

The idea for starting services in the area had begun two years earlier. A community survey of 112 caregivers, many of them Alzheimer's Disease families, had indicated that their primary need was the ability to get away from their caregiving responsibilities for "a few hours now and then."

With this information, a community-based task force of 22 individuals representing home health agencies, social service agencies, hospitals, churches, colleges, the nursing profession and caregivers met for nearly a year planning the program and trying to secure funding. The group formulated goals and some very basic guidelines for the program. The primary purpose was to prevent premature or inappropriate institutionalization of the frail or impaired elderly by providing short-term respite care. The committee decided: 1. the program would be accessible to all income levels; 2. there would be no limitations on the number of times respite care could be provided to a family; 3. although the program might expand, initially services would be directed at providing respite breaks of a "few hours or more" and, 4. the program would use paid and trained providers.

Although I was not part of this decision-making process, these guidelines were excellent and showed considerable thought and research to make this program a success.

Under the name of Good Samaritan Hospital & Medical Center, the task force applied for and received monies from the Area Agency on Aging to develop a training program for providers. A second funding award was received by the local Alzheimer's Disease and Related Disorders Association from an Oregon foundation to set up the program. The $56,482 was awarded in fall, 1983 and was expected to cover an 18-month period. It has actually lasted 26 months. At the time it was decided the program would be co-sponsored by the ADRDA and Good Samaritan. The ADRDA had offices at Good Samaritan. The co-sponsorship gave access to different areas of expertise. The hospital, an established and respected community institution, provided support in the areas of accounting, risk management, marketing and administration. It also donated space, telephone and mail services and equipment. The ADRDA, a very new organization, provided time and direct access to families, their needs and concerns.

The new program was called the Senior Respite Care Program. Although it primarily focuses on Alzheimer's Disease, the program serves families caring for anyone over 60 years of age and/or coping with dementia. We are in the process of changing the name to Caregiver Respite Program which we feel better describes our services.

Hiring a director was completed by early December. My prior experience included administering a family planning agency in New

York State. As director, I had been responsible for grant proposals, budgeting, planning and staffing. I had had no experience in working with the elderly or directly with clients. This caused some concern among the hiring committee and I was interviewed a second time before a final decision was made.

Looking back I think the committee made a wise decision hiring an individual with strong administrative experience. There were basically no program policies and someone had to develop fee schedules, payment and billing arrangements, etc. as well as deal with liability issues. Additionally the challenge of future funding had to be tackled almost immediately. Eighteen months is a very short time to develop, implement and find continued support for the program. In addition to administrative duties, I was also responsible for training providers. In family planning, clinics have a position called "All Purpose Person" and this title aptly described my new job.

I spent the first month planning how to operate the program and familiarizing myself with both the aging process and Alzheimer's Disease. The director of ADRDA was an invaluable resource in helping me formulate operation guidelines. Because respite care is such a new service, we had no way of knowing what worked and what didn't work.

First of all we had to decide who should receive respite and for how many hours. Since the costs of operating the program were subsidized by a foundation grant, we wanted to insure that as many families received the service as possible. We also wanted to focus the program on homebound caregivers who needed "a few hours now and then" versus the working caregiver or someone who had to be out of the house for extended periods. We decided to limit the number of hours to 16 per week per family. After two years of operation, I would suggest that 10-12 hours a week is the maximum most families want for respite care. Indeed most caregivers schedule less than six hours per week.

Defining service limitations was a bit more difficult. The task force had defined respite care as "care provided by a substitute care provider which allows the resident to be away for one or more hours." This provided little information on what the respite provider would do during the visit. The intent of the program was not to duplicate services in the area and respite providers are not home health aides. We decided that respite providers would help with eating and toileting but not bathing.

We simplified the definition of respite care to "supervised companionship." I am quite firm with families about exactly what the provider can and can not do. In the beginning, there was a great deal of confusion and respite providers were mowing lawns, giving baths and even defrosting refrigerators. At one home, the provider cooked the family meals for an entire week and froze them. When I had to replace her, the family was most dissatisfied with the new provider because she didn't cook. Providers also cannot administer medications or drive the impaired individual anywhere. We have made further limitations and now say in an introductory letter about the program that we don't lift (we help transfer) or deal with "heavy" incontinence.

The fee schedule is based on the federal poverty guidelines.

It is a sliding fee scale with the lowest fee $2 per hour and the highest $5. We charge according to household income. We reasoned the family was purchasing services not the impaired person. Any household with incomes 200% above the poverty level pays full fee. The task force had decided that everyone would pay some fee and initially the lowest fee was $1. We raised it to $2 in summer, 1985.

Originally we had five fee levels with the highest being $7 and $8 per hour. Using this schedule we felt we could make the program self-sufficient with a high enough volume.

We quickly lowered the high fee. We did not want to be in competition with the home health agencies. There was a second important reason. The intent of the program is to actually encourage families to take regular breaks from caregiving by offering low cost and convenient services. I, myself, was more comfortable with $5 as a maximum fee. It was easier to discuss fees with families. We are essentially the lowest rate in town. Even private providers usually charge $5 per hour. By serving all income levels, we are also able to avoid the stigma of being a "welfare agency." Today at least half of our clients pay $5 per hour.

I now send out the fee schedule with the application. The fee schedule contains instructions on how to figure out the appropriate fee. I never ask families for documentation and I accept what they say they ought to pay. In the two years of operation, only three families have indicated a fee lower than what I felt it should be. I should also add that we experience very little difficulty on collecting fees from families. We rarely have anyone who owes us money. A professional caregiver is the only client who has left the program with an outstanding bill.

The liability issue which appeared to be an enormous problem was not. The hospital assumed liability for the program under its general insurance policy. It costs the hospital about 75 cents per encounter. I did some checking about liability polices and it seemed they were readily available on the market. The hospital's risk management department advised us against having the providers bonded as the only way a family can collect is by a conviction in court. The chance of getting a conviction with an Alzheimer's Disease victim in the house is slim. We have never had any problem with thievery. One family which had been "burned" before left rings and money around their home to see if a provider would pocket them. After six months, the caregiver told the provider she had passed their test and was completely trustworthy. I only hire individuals who are established in the community or are enrolled in school.

Providers are paid $3.35 per hour. Providers are independent contractors with the hospital and nothing is taken out of their pay which minimizes the bookkeeping. The hospital does all the bookkeeping for the program. At first we did not pay transportation but found it increasingly difficult to get providers to travel more than a few miles. We now reimburse 21 cents per mile or pay bus fare. Providers can be paid as often as twice a week. Some wait until they fill in their time sheets;

others send in time sheets each week. If someone really has an emergency we ask the accounting department to cut a check. It is important to pay providers frequently as a method of reward. Families are billed monthly, and we have to watch the cash flow. If we have a light month followed by a heavy usage month, our cash reserves dwindle. Respite care use tends to have cycles. November and December are traditionally light months with summer and fall fairly heavy.

IMPLEMENTATION

Program operations began in 1/84 with the recruitment of providers. We had long debates about what type of provider we should recruit. Some individuals felt that nursing students would be excellent providers and easily recruited. ADRDA members strongly disagreed feeling that most families would feel more comfortable with an older and more mature person. I have hired both college students and older individuals and have found all ages to be suitable. However, I have found that middle age and older people are more likely to stay with the program reducing the turnover rate. I even have providers who previously received services from our program.

One of my greatest fears was that nobody would apply to be a respite provider. It seemed unlikely that anyone would want a job that required a great deal of patience, was possibly boring and paid so little. A single advertisement in the Sunday paper brought over 100 responses. Our application form is an excellent screening tool. It includes a checklist of different situations people indicate they can handle. The list includes: controlled seizures, belligerence, incontinence, confusion, etc. Only 25 applications of the 100 were returned. Some people think that respite care is easy work. It is not. I know I went out on an assignment to see what the work was like. I could hardly wait for the four hours to end.

We charge $25 for training and return the money to the individual after they have logged 24 respite care hours. In the beginning, I negotiated with individuals who couldn't afford the training fee. I no longer do this for consistently they quit before they provide the 24 hours.

I interview each applicant and check references before accepting them for training. I have learned a great deal about hiring providers. I usually don't hire smokers, individuals who are looking for full-time work or who really need the money. If an individual indicates they can only work a minimal number of hours or travel within a very small geographical area, I don't bother to train them. Respite care work is not steady. One month you may have five families and the next month, four of them are no longer with the program.

Some people just aren't suited for respite care. I hired one woman who later dropped out because she became so bored and nervous while providing care. She found she worked better with small children.

I also don't hire people who tell me in great length about their personal problems during the interview. I do not solicit such information and I can't believe families in stress will want to hear such information. I still make mistakes in hiring. Sometimes I am too eager to get a new provider and hire despite some misgivings. At the beginning I was training every month which is exhausting and time consuming. Now I train only a few times each year. Most of the providers have been with the program for at least a year. They are caring, calm and extremely competent individuals and many have a special relationship with their families.

I really consider them volunteers and I work hard to be as flexible as possible with their schedules. If they want to take a vacation, I arrange for substitute help. Some providers took the entire summer off. Since I have students who are looking for work during the holidays and vacations, this is an ideal situation. I also talk with most of my providers at least twice a month. I consider them peers working with me to provide a quality service. Because of that, I think they feel that what they are doing is worthwhile. We do provide a minimal raise each year.

Before accepting anyone for training, references are checked by mail so we have a permanent record. The reference form asks several probing questions including: "Would you trust this person to provide respite care in your home?" Some responses have indicated problems not apparent during the interview or on the application. Although it may not be fair, if there is any indication of a problem I don't hire the individual. One day as I was interviewing an applicant I thought I smelled alcohol. I wasn't sure and the janitor had been cleaning with chemicals quite near us. The reference check indicated there had been a problem with alcoholism in the past. I didn't hire the individual and I still don't know whether I really smelled alcohol but the combination of the smell and reference check made me decide against the person. Some agencies who are working with the unemployed or disabled have tried to use our program as as way to meet their program's goals. Most of time this hasn't worked out. We are not in the business to rehabilitate providers.

Training usually takes two full days. The training program was developed by the caregiver education coordinator at Good Samaritan. I, who had no background in aging or Alzheimer's Disease and had never taught in my life, can provide a very good training program. The program not only sensitizes individuals to the aging process but also shows them management skills. It is really remarkable to see people who know nothing about Alzheimer's Disease begin to discuss ways of handling problem situations. Not only do they have an understanding of the disease process but also some of the techniques for working with impaired individuals. We have recently added training sections on Stroke and Parkinsonism, populations who may also suffer from dementia but need different care. During the training session, the group meets with a stroke recoveree and Alzheimer's Disease and Parkinsonism caregivers. They have an opportunity to learn first hand about the impact of these chronic disorders.

The first training program had nine individuals. That many people made interaction lively. However after training, I had nine people wanting to work, eager to apply their new knowledge to a home situation. Unfortunately I had no families. I learned a painful lesson not to hire more people than you can place. Once individuals are trained, it is difficult for them to wait for work. Most will leave the program within a few weeks. If I can not place an individual within a month, I return their $25 training fee. I now only train two to three people at a time.

Training gives me an opportunity to view the potential providers for an extended period. There have been a few I have trained but never placed. There was something that made me uncomfortable during the training. The bottom line for me is how I would feel about this person taking care of my mother or father.

Lack of families was very worrisome. After all the community survey had indicated a great need for respite care in the Portland area. I only had one family in the first month and two in the second. There was no way I could check my experiences with other programs as respite care was so new. I now know it is a common experience and it takes a long time to build up a clientele. To new programs I caution patience. Even as an established program we only add six to eight families per month. At the same time we may lose six to eight to placement or for other reasons. In one year, a program could serve 150 families but only average 40 to 50 families per month.

There are barriers to respite care. Many families are unaware of the service or even what the word "respite" means. They are afraid of strangers being in their home. They are ashamed they can no longer take care of their loved ones and have to seek outside help. They feel guilty about spending even a small amount of money for services. Women, in particular, devalue their time. They want on-call services and do not want to commit themselves to a set time period. Often women tell me "they only want to go shopping once in while." Male caregivers are more likely to schedule regular respite sessions for recreational purposes - swimming, golf, bridge, etc. Men and adult children also seem to schedule respite care earlier in the disease process than female spouses. Quite often I am called into a home with a wife caregiver after some crisis has occurred. Several times permanent placement has occurred just before or shortly after we started respite care.

Being aligned with the hospital and the ADRDA gave the Senior Respite Care Program a great deal of credibility in the community. One of the best marketing tools is a flier about the program inserted in every ADRDA information packet. Paid advertising did not work at all but an appearance on a local television station brought a lot of requests for information. I try to meet with support groups and speak at community gatherings. A face-to-face encounter seems to be a very effective way in reaching families.

We have had tremendous support from human services agencies, hospitals and home health agencies. We made every effort to structure our program to link with other services, not take their place. Interestingly most referrals from home health agencies and hospitals do not work out. Many of these referrals have health care problems which we can't handle. We actually serve the hidden caregiver. Most have had no experience with the human services network. The impaired person is displaying problem behaviors which require constant supervision or for some reason can not be left alone. Often my first impresssion on making a home visit is that there has been a death in the house. Usually the home is silent and often the drapes are pulled. Everyone including myself talks in a hushed tone.

An excellent source of referrals is the physician community. Female caregivers often call me after their doctors have "ordered" them to get help. Doctors, however, still don't refer as often as they should.

I developed a very set process for linking caregivers with providers. After an inquiry or referral, I would schedule a home visit, usually within two days. I would meet with the caregiver for about an hour and then at the office contact a provider. The provider would call the family and schedule a time to meet the family. If everything went well, respite care would begin on a weekly or bi-weekly basis. After the first respite visit, I would contact the family to make sure everything was going smoothly and encourage them to call if there was a problem. Initially I sent out a written evaluation but found that caregivers were annoyed at having one more piece of paper to fill out. Sometimes the caregiver may have to wait a week or so if I don't have any providers free but most can start care immediately. One thing about this program is that it is never stagnant. One week I need families, the next I need providers.

We have changed the system slightly. I found during the first year, I was making needless home visits. In fact for every two visits, I only made one placement. Even though I had talked to the caregiver on the telephone, when I got to the home the caregiver didn't really want respite care, didn't want to pay, needed weekends, etc. I was on the road everyday and the home visits were quite lengthy. Finally a colleague advised me to begin sending materials, application and fee schedule to the caregiver and require they be sent back before the home visit. The system has worked very well. Sometimes after reading the application, I know we can't handle the situation and refer the family to an appropriate agency. I now make a placement for almost every home visit and have much more free time. Having reduced two very time consuming processes - training and hiring new providers and making needless home visits, the amount of work is less and the program could expand significantly with the same amount of staff.

When I make a home visit, I try to encourage families to use alternative respite programs. In-home care is the most expensive form of respite and there are several adult day care centers available in the area. Many offer transportation as well as bathing for a nominal fee. For some families, day care is not an option. Others I have been able to direct to these programs. We have also developed lists of nursing homes who provide over-night respite care. Getting families to plan for emergencies or for the future is difficult but I give them as much material as is available. We try to include information in every billing to families. If I find a good article on Alzheimer's Disease and dentristry, we enclose it with the bill. Lack of information seems one of the biggest barriers to getting help. Families rely on the program for information and often call when they encounter a new problem or need help in obtaining services or placement.

Originally we put no minimum amount of time for families and immediately ran into the problem of caregivers wanting an hour or two. Trying to find a respite provider who was willing to go into the home for an hour was near impossible. I also have doubts whether one hour or two is sufficient time to give a break. At a minimum I think four hours is necessary but we have set our minimum amount of time at three hours at least every other week.

Our hours are Monday through Friday, 8 a.m. to 5 p.m. There is always someone in the office when there is a problem. An advantage to having our office at the hospital with the ADRDA and 13 other support groups is that someone can always cover for me if I am on a home visit. We did start the program by offering evening hours but most caregivers don't out in the evening. Again, I had people trained and no where to place them. We limit our services to weekday hours. Extended family, friends and neighbors as well as volunteer organizations often provide respite during the weekend. I am surprised, however, at the number of churches which have no programs to allow caregivers to go to church. So often, this is the one thing the caregiver misses the most.

Because we include so much information about the program in the packet we send out in response to an inquiry, the home visits usually last about 30 minutes. My purpose in a home visit is to meet the caregiver and to get some feel for the type of care that is needed. The home visit also helps me to work with the respite providers if there is a problem. At least I have met the family and impaired person and have a point of reference. If the individual is having a catastrophic reaction, I know their size and whether the provider can handle a bad reaction. I am also able to brief the respite provider about the family before the visit in addition to giving them a copy of the application.

REFINING THE PROGRAM

By 7/84, we had provided services for six months and had served 40 families. I had six providers on contract although I had trained more than 25. Most I couldn´t place and lost to other work. We were beginning to get a balance of families paying different fees and by September the fees were paying for all the costs to the providers including their mileage. Record keeping was relatively simple. The only ongoing work for the full-time secretary was the monthly billing and making check requests for provider payments. It became clear that I did not need a full-time secretary and we dropped her hours to 18 per week.

In July we entered into a contract with the Area Agency on Aging in an adjacent county to provide respite services. The Area Agency on Aging paid us $5.35 per hour minus what we collected from families. The fee schedule used by the county and throughout the state for home health services was slightly more liberal than the one we developed. Also, adult children's income was not included in computing the fee if they were caring for a parent. Only the parent's income was counted and so many families paid nothing for respite care.

At the end of the first year, we did not bid to continue services. We may bid in 7/86 if we can work out a cooperative arrangement with RSVP to find providers. My biggest problem in serving the county was the geographic distance. Not only was I traveling every day but also I simply could not find local providers. I had to send providers from metropolitan Portland to provide respite care 20 or 30 miles away and transportation was extremely costly.

There were a number of differences between programs run on private funding and public funding. All of a sudden I had a great deal more paperwork and meetings to attend. I was spending a higher proportion of my time in the county where I was serving less familes. One form I had to fill out assessed the risk of institutionalization for the impaired person. (Respite was being funded under the Medicaid waiver.) The form focused mainly on the physical ability of the individual. Alzheimer's Disease victims tended to rate at low or moderate risk and the physically handicapped at high risk. Yet the Alzheimer's Disease victim could not be left alone even to run to the store for a few minutes. At one point, I was told to drop services to moderate or low risk individuals. I did not have to because the contract ran out before I had to take action. But it seems that there is a need not only to educate the public about dementia but government officials too.

There was also a different orientation to the program. Since I was on a limited budget with the county, I had to decide who would get services. No longer did the family have the control, I did. The program was not complementing family management, it was supplanting it. I think it would have been better for families to pay some fee and have additional income rather than having me ration services.

Within the next 12 months, we encountered every problem we thought could happen but probably wouldn't. Many of them were caused by me stepping out of the program guidelines. For a time, I tried to help everyone. I learned the hard way that the only thing we did well was to provide short-term respite to caregivers. Amazingly the initial guidelines established for the program have only been modified slightly.

In a short time I learned that the program could not provide respite when the caregiver did not live in the same house. We had been asked to check in on relatives while a family was on vacation. Nor could we be part of a piecemeal of services for the working caregiver. Our program works well because three people are assuring quality control. The caregiver who does not feel her mother is being taken to the bathroom often enough will call me after the first visit or talk to the provider. The provider who has a problem can immediately solve it when the caregiver returns. If someone becomes ill or can't travel in an ice storm, the respite visit can be cancelled. Because we had problems with these situations, we only provide services when the caregiver is at home when the provider arrives and returns.

Although there is a great need for relief for foster care providers and professional caregivers, we decided we would concentrate only on families. The one time we did provide respite for a professional caregiver, she quit her job and left us with an outstanding bill.

Twice I tried to help families get live-in help by matching one of my providers whom I couldn't place. Both times, the match didn't work and the families were very annoyed at me. I now refer families to placement agencies. Locating live-in or or extended home help is very troublesome and a low cost placement service would be a nice addition to the program. We have requested foundation funds to expand our program into this area.

I have tried to keep the program as informal and flexible as possible. This is a support service for an informal caregiving system. Families and respite providers can change schedules, cancel visits (if not too often), and even arrange for private care between themselves during non-office hours. I do not give the provider's home phone number to the family but I encourage the provider and caregiver to make their own arrangements but keep me informed of any changes in schedule. I know where the providers are during the week. Some of them have served the same families for months, one for nearly two years.

We lose several families every month. Right after Christmas seems to be a time for placement. Usually we know when placement is imminent. The caregiver and provider have discussed the situation and we frequently furnish materials to help make the decision easier. The hospital has an excellent education program for caregivers and we have audiotapes and written materials both on nursing home and foster home placement. This is a very difficult time for the caregiver and I like to think our help and concern eases the pain.

When a respite provider is ill, generally the caregiver does not want a replacement. Usually another time can be substituted. The program is successful because we send the same person every week. High provider turnover does create problems as caregivers do not like have to acquaint new providers with their family and their home.

I used to spend a great deal of time on the matching process. I have learned, however, that if I do correct hiring, most families are pleased with whom I send. I have excellent providers, several have medical backgrounds. Others have worked in nursing homes and many have had personal experiences with caring for the disabled or elderly.

The providers work very hard to make the respite visit pleasant for the impaired person. They take them on walks, bring books from the library, play games, etc. One home a minister with Alzheimer's Disease and the provider talked about his sermons. The man was in the late stages of Alzheimer's Disease and the family even had hired additional help. We thought perhaps we weren't needed but the family said the few hours spent with our provider was the only time during the week the elderly man had some dignity restored to his life.

If a match doesn't work I replace the provider. Usually matching is more of a problem for the provider. Since I generally don't hire smokers, finding someone to provide respite in a house of smokers is difficult. One time, we provided services in a home that was both filthy and flea-ridden. The caregiver was exhausted and seemed both to me and the provider unable to get the energy to clean. The provider bought a flea collar for the dog and persuaded the caregiver to get the rugs cleaned and the house fumigated. We also were able to get her housekeeping services though the senior center.

I try to balance easy and pleasant respite assignments with hard ones. I "burned-out" several providers before I realized this.

We are often able to link caregivers with other services. I include time during the training program to talk about community resources. The Veterans Administration in Vancouver, Washington has a free two week residential respite program for veterans. Several of our families have used this service and reported having a wonderful two week break. Most caregivers have no idea how to negotiate the human services network so we make the referral for them. Providers have also located services on their own including finding firewood for a family in need or signing up the family for bookmobile library services.

Families unable to obtain much help from the community are those caring for dementia victims under the age of 60 years. Home care services such as Meals-on-Wheels and personal care

are available only to the elderly. Our program is one of the few that makes an exception and serves Alzheimer's Disease families regardless of age. We now make the same exception for stroke and Parkinsonism. Although our training covers management behavior, I never really expected we would encounter some of the problems we talked about. Well, we have had them all and others we didn't expect. I have found that despite a home visit and an extensive application form, families are not always honest about problem behaviors. Partially this comes from embarrassment, a fear that services will be denied or a belief that the behavior happens only around the caregiver.

We have dealt with belligerence, sexual exposure and drinking. Most of the time, we have worked with the caregiver and have been able to continue services in the home. One Alzheimer's Disease victim was extremely hostile to a provider and spent all the time loudly complaining about her. The provider was very upset and I went back for a second home visit. It turned out that the woman did not like fat people. I replaced the provider with a thin person and there were no further problems.

On another assignment, the Alzheimer's Disease victim began digging up the flowers in the garden. The provider could not distract nor make him stop. Short of physically restraining him, there was nothing she could do. Naturally the caregiver was very upset when she arrived home and told the provider she should have slapped the man to make him stop. We stopped providing services in that household.

We have had a few problems with caregivers. One caregiver grabbed a young respite provider and kissed her. The caregiver desperately needed respite so I solved this situation by replacing the provider with a larger and older woman who towered over the caregiver.

I have only turned down one family for services after a home visit because of a behavior problem. The individual suffered from Alzheimer's Disease and Parkinsonism and was a retired minister. He was extremely hostile to me during the home visit. One minute he would be speaking calmly and the next demanding to know if I was saved. At one point he shook his fist at me. I did not want to place a provider alone with him. I learned later he frequently hit his wife.

Women seem to have a difficult time arranging for respite care. Quite often they want to bring the impaired person into the discussion about services. Of course, he wants nothing to do with me and if the subject of fee arises, he usually orders me out of the house. Often female caregivers cry during a home visit. I can well imagine how difficult it is to talk to a stranger about these highly personal problems.

Extended families are extremely supportive of respite care. Sometimes the children contact the program and arrange for services. After some 300 home visits, I am aware that caregivers are reluctant to impose on their families and often would rather pay for services than ask for help from the family. I think many times the extended family could help more but simply doesn't know how. Lack of help from my perspective is generally not an unwillingness but just not knowing what to do.

Caregivers are often very concerned about leaving their loved ones and think the impaired person will never accept a stranger. We really have had no problem if the caregiver simply leaves. When the caregiver makes a fuss usually the leaving is very difficult.

Although many caregivers think a man would provide good company for their husbands or fathers, this has generally not been so. Quite often the male provider is seen as a threat. One 96 year-old-man locked the male provider out of the home. Male stroke recoverees are often very hostile to a male provider. When I talk to the families about the situation, usually there has been a similar incident with a male relative or in-law.

We have had very few emergencies on the program. Generally the individuals we care for are physically healthy. Indeed it is often the caregiver who is suffering from ill health. Five times in 11,000 hours of service, providers have called an ambulance. None of the situations have involved Alzheimer´s Disease victims and two have involved the caregiver. One caregiver had immediate brain surgery after the respite provider got medical help and the family credits the provider with saving their father´s life.

We also have had two near disasters. One provider left an Alzheimer´s Disease victim alone when her time was completed. She thought another family member was in the house and left as she had been instructed to do a prior time. Nothing happened but certainly the potential was there. After that we required that time sheets be signed after each visit. Last summer, one of our providers contracted tuberculosis. Fortunately his families tested negative but we now require a yearly TB test.

There may be more problems. I usually try to keep in contact with the caregiver and always call right after the first assignments. We did an evaluation of the program and received "rave" reviews from caregivers. Yet I know caregivers are loathe to complain and I now call each caregiver at least quarterly to chat.

One area where the program fails families is when the impaired person begins to requires different care than we can provide. If the individual becomes bedridden, totally incontinent or seriously ill, the level of care increases. For three families, we have stopped services. Unfortunately there is no higher level of respite to replace us. Just when the caregiver may need time to make personal arrangements, there is no help.

ESTABLISHMENT, EXPANSION AND THE FUTURE

At the end of first full year of operation, the program had provided respite care to 75 families and logged 4,026 hours. The majority of cargivers were spouses, 28 wives, 14 husbands, followed by 23 adult daughters. Most of the families (37) were caring for Alzheimer's Disease victims, 12 for stroke recoverees and 10 for the frail elderly.

By the end of the first year, the foundation monies were primarily being used for salary and fringe. Less than $5,000 during the first year went to supplies and payment to providers. Total cost of operating the program after deducting income was $34,000.

In the second year, the foundation funds were used exclusively for salary and fringe. The money collected from families not only paid the providers and their transportation costs but also purchased supplies. The hospital continued to provide in-kind support. Family payments amounted to $33,600 out of a total budget of $60,390. We nearly doubled the hours of service to over 7,000 and expect they will increase to 11,000 in 1986.

Quite obviously, a critical issue facing the Senior Respite Care Program is funding. To make the program self-sufficient, each family would have to pay $7.50 per hour. (As volume increases the hourly rate is reduced.) Services at this price are already available in the community from private agencies or individuals.

Not many families can afford these high fees. One caregiver wrote on the initial community survey: "In my case, we are too rich for outside help and too poor to afford to pay for it ourselves."

While the subsidized costs of the program have steadily decreased, the program is far from self-sufficient. As the program grows toward its goal of serving 200 families each year, income for administrative expenses is expected to reach $1,000 or more per month. Presently we are studying ways to expand the funding base. Potential sources of income are from government contracts, donations and development of new income producing services. The program is also seeking foundation funds to move the programfrom its developmental stage to a cost-effective service. Unfortunately most foundations do not like to provide funding for ongoing operations. Approximately $6,000 of our income per year comes from sale of materials and consultations/honorariums.

The program receives a great deal of support from the hospital. The hospital formula for computing in-kind support put its donation to the program at over $20,000 a year. This includes direct services as well as administering the program. I report regularly to the director of the Neurological Sciences Center Education and Family Support Project of Good Samaritan Hospital and Medical Center. Other respite programs that are starting are also linked to an established agency. The Denver and Orange County chapters of ADRDA are developing similarly-structured programs to ours. Once a respite care program is established, it requires less and less administrative time. This provides me the opportunity to expand services and seek additional funding.

Certainly the case for respite care is hampered by the lack of research programs which document its effectiveness at reducing institutionalization. That respite care reduces caregiver burden must certainly be true. Our own experience with families testifies to this fact. We have provided respite care in homes up to a few weeks before death. The caregivers have told us that they would not have been able to keep the impaired individual at home without regular respite services.

At the least respite care strengthens the caregiver's ability to keep the relative or spouse at home. However, it seems to me that each family has established personal criteria on when to place. Some families can not deal with incontinence or violent behavior. No matter how much respite is provided, families place when these situations occur. Others are determined to keep the impaired person out of a nursing home and will do so at any cost.

I have hardly mentioned any board or formal structure to the respite care program. Other groups interested in developing respite care programs often ask for descriptions of the advisory board and its functions.

The program does have an advisory board which includes a physician, educator, respite provider, government official, ADRDA representative and a nurse practitioner. The advisory board meets infrequently. Because the program is co-sponsored by both a hospital and the ADRDA, I turn for counsel from both organizations. If I need financial help, the hospital staff is there to meet with me. If I have to make a decision concerning policy affecting families, I have ADRDA members to help me. Other organizations may have to rely more on the expertise from an advisory board if they lack the combination of talent provided for me.

The future of the program depends largely upon its funding. If we receive approval of the foundation grant, we will be able to expand services and hopefully achieve near self-sufficiency with continued hospital support. If the proposal is turned down, other funding avenues will have to be sought. My belief is given the time, the program could become cost effective and require minimal subsidy.

Experiences of the Atlanta Area ADRDA in the Development and Management of the Community Services Program

April 1986

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EXPERIENCES IN THE DEVELOPMENT AND MANAGEMENT OF THE COMMUNITY SERVICES PROGRAM OF THE ATLANTA AREA CHAPTER ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.

This paper describes the experiences of the Atlanta Area ADRDA Chapter over a two year period in the development, establishment, and direction of a Community Services Program for persons with Alzheimer's disease and related disorders. The Program includes three services: a specialized day care center, in-home respite care services, and education and training of staff, volunteers, and the community.

I. DEVELOPMENT OF COMMUNITY SERVICES PROGRAM

A. Early History of Chapter

The Atlanta Area Chapter of the Alzheimer's Disease and Related Disorders Association was organized, incorporated and affiliated with the national ADRDA in 1982. The Chapter's development was the outgrowth of concern originating from staff of an adult day care center. At that time, many families were turning to the Center for help, sometimes as a last resort, after exhausting themselves physically and emotionally. Both staff and families were perplexed by the difficult behavior expressed by these Alzheimer's patients, many of whom had not been diagnosed as such, and sought information about diagnosis, cause, and services to help relieve the family of some of the burden. After searching the community for resources, and discovering that there were none, the Center held a meeting to which representatives of other concerned agencies and families known to be dealing with the problem were invited. At this initial meeting, at which a prominent neurologist spoke, the need for an organization which could provide information and support for families was affirmed, with plans being laid for a steering committee to guide future development.

This early history is significant because the staff who were involved with this day care center and were aware of the benefits of such a service to families have continued to be active in the leadership of the Chapter - one as Executive Director and another as Chair of the Board Committee which developed the Community Services Program.

B. Development of Concept for Program

Since the organization of the Chapter and its identification as a resource for family members, the need for additional services to assist persons caring for Alzheimer's patients in the home has been brought to its attention. Calls to the Chapter Office requesting assistance in the home confirmed that families chose to keep their relatives at home for as long as possible. Yet in surveying community agencies to find various alternatives for services, few were found to exist. Members of the Chapter's support groups also complained about the dearth of community resources.

In order to address the issue of limited services and resources and seek solutions to the problems of families, a Chapter Committee on Home Care was organized. The first step of the Committee was to develop a Home Care Survey which requested from persons on the ADRDA mailing list certain specific information about home care needs and experiences.

Based on the information from the Survey, the Chapter made the following conclusions:

(1) Agencies providing various levels of assistance in the home did not supply proper training for caring for Alzheimer's patients.

(2) The cost of care was too expensive for many families.

(3) Paid companions often "burned out" because of the demands of the job, confinement, and boredom.

(4) Many families were not using paid outside help, even though the extent of care would indicate the need for some assistance.

(5) Many victims receiving care at home could be considered candidates for skilled nursing home care because of the high level of physical care needed.

Faced with the overwhelming nature of these findings, the Chapter sought to develop programs which would make some impact on these problems. The first opportunity to develop such a program was in July, 1983 in cooperation with the Visiting Nurse Association of Metro Atlanta and the Seniors in Community Service Program of the Atlanta Urban League.

The project consisted of persons who had low-incomes and were 55 years of age and older, who participated in a 240 hour training program which included 56 hours of classroom instruction and field practicum, and 184 hours of on-the-job training. The classroom portion of the training covered the Companion/Attendant/Sitter curriculum provided by VNA (32 hours), 8 hours of information on Alzheimer's disease and patient care, and 16 hours of experience in a nursing home, working with Alzheimer's patients. The Atlanta Urban League recruited and screened applicants, the VNA conducted the training program, and ADRDA provided the content for the training on Alzheimer's disease as well informing families about the availability of the workers. The workers were paid for their training time through funding from Title V of the Older Americans Act. During the on-the-job training portion of the program, families using the workers paid $3.35 per hour for their services. Following the training, the workers made independent financial arrangements with families. Workers who were not employed by families were placed on the Companion/Attendant/Sitter Registry of VNA and available as needed for work assignments.

Unfortunately, because the funding for the workers was not available after the first class of workers, the full potential of the opportunity was not realized. However, the original concept for the program is still valid, and several residual long-term benefits were gained:

(1) The program established a relationship with VNA to include information on Alzheimer's disease as a part of its curriculum for Companion/Attendants/Sitters. In addition, ADRDA has cooperated with VNA in training sessions for other levels of nursing care - home health aides, registered nurses, etc. Also, ADRDA has developed relationships with other home health agencies, companion services, and county-based aging agencies, for the purpose of conducting training on Alzheimer's disease.

(2) The preparation of written materials for the training sessions provided the stimulus for the development of the Chapter's booklet, Understanding and Caring for the Person with Alzheimer's Disease: A Practical Guide. This booklet, which the Chapter first published in late 1983, contains the answers to commonly asked questions about Alzheimer's disease, discusses the impact

of the disease on the family, and gives tips on caring and communicating with the person with Alzheimer's disease. The Guide was written for the purpose of providing information to the "hands-on" caregiver. The booklet, revised in the fall of 1985, has sold over 6,000 copies across the country through other ADRDA Chapters and other interested agencies.

(3) The Program confirmed the premise that training is beneficial in preparing workers for accepting assignments with persons with Alzheimer's disease, and that families are more confident with a prepared worker.

C. ADRDA Board Commitment to Program

In early 1984, the Chapter staff expanded to include two full time positions, Executive Director and Office Coordinator, who with additional volunteer help provided the increasing volume of basic Chapter services of information and education, support group development, and advocacy.

The awareness of the Home Care Committee to seek additional patient care related activities led to the formation of an additional Committee of the Board, charged with the development of a plan for a Day Care Center which would offer specialized care for the person with Alzheimer's disease. The Home Care and Day Care Committees, composed of family members and interested professionals, worked closely with the Executive Director in developing the concept of a "Community Services Program" which offered two options to families caring for the patient in the home setting and included four components.

(1) A Daytime Care Center

(2) In-Home/Respite Care Services

(3) Training Center

(4) Research Program

The four components were envisioned to complement each other and work in close cooperation. The projected staff included a social worker, registered nurse, occupational therapist, and educational coordinator. Employment of three para-professionals and two doctoral psychology students from Georgia State University was planned. The Committee also recommended that volunteers be a vital part of the program. Although the program would employ professionals to provide the direct services, the administration of the program would be the ADRDA Chapter, which is governed primarily by family members. The program would thus combine the talents and concerns of both areas to create an effective partnership.

It was planned to initiate the Program with the Day Care Center and In-Home Respite Program. The development of the Training Center would follow when appropriate funding was secured. Research would be done in conjunction with local colleges and universities, with the Community Services Program providing the participants for research projects.

This concept for the Community Services Program was approved by the ADRDA Board of Directors in January, 1984, with the cautionary note that the funding required for such a large undertaking would be substantial. However, the reservations about the financial impact of such a program were outweighed by the overwhelming need of the families requesting services and the fact that other groups or agencies were not addressing the problem.

II. ESTABLISHMENT OF PROGRAM

A. Development of Funding Sources

Local Foundations: The responsibility for attracting the financial resources to implement the program was given to the Board's Fund-Raising Committee and Board approval was given to the engagement of a local fund-raising consulting firm for assistance. A Case Statement was developed which provided potential contributors with the facts about Alzheimer's disease, the history of the Chapter and the needs of families for a Community Services Program.

The major start-up money of $50,000 was provided by one local foundation which requested anonymity. An additional $7,000 had been raised by the end of 1984 from individuals and community groups. This was deemed a sufficient amount to begin the program in 1985, with the recognition that additional fund-raising activities would need to place early in 1985 to meet the budget of $188,000 required to fully implement the program.

Sliding Fee Scale: The recommendation was made that users of the Community Services Program contribute to its financial base with fees based on the income of the person with Alzheimer's disease. The long-term financial consequences of Alzheimer's were recognized, and the Committee created a scale that ranged from $3.50 to $25 per day. The same scale was proposed to be used for both day care and respite care, with 3 hours of respite care being equal to one day of day care. The scale was adjusted upward by $1.50 per increment after three months' experience in the program. This decision was made after it was found that the majority of participants in the program were at the lower fee levels, and an insufficient amount of income was being realized. The fee scale (Attachment A) currently ranges from $5.00 per day to $26.50.

Public Sources

State Office of Aging: In April, 1984, a meeting was held with the State Office of Aging, and resulted in an item of $115,000 added to their supplemental budget. However, because the appropriation was not given a sufficiently high priority ranking (#29) by the Department of Human Resources, funds were not approved. This effort was not entirely fruitless because it did pave the way for a larger request proposed for FY1987 funding. This latter request, for $374,500, was ranked #2 Priority by the Office of Aging, and when consolidated with requests from other divisions of the Department of Human Resources (the umbrella agency in which the Office of Aging sits) was ranked #19 when submitted to the Governor. Unfortunately, the Governor did not recommend its funding when his budget was submitted to the General Assembly in January, 1986.

The Chapter's two registered advocates, a coalition of other advocacy organizations, and Chapter members worked hard during the two month General Assembly Session to assure that the funding was placed back in the budget. The outcome of this effort was that $187,000 was approved to help support the Chapter's current Community Services Program, initiate another Day Center under the Chapter's auspices, and fund two other programs in the state. While only half of what was requested was approved, the Chapter is pleased that this amount was appropriated especially considering the Gramm-Rudman impact which made legislators extremely conservative about funding new programs.

Area Agency on Aging, the Atlanta Regional Commission: The Chapter has been successful in obtaining grants from the Aging Division of the Atlanta Regional Commission, for FY86 and FY87. These Title III grants were for $23,800 in FY86 and $22,395 for FY87. The process began in January, 1985 when ARC established a competitive bid process for funds for specialized programs which provided services to meet specific priorities, one of which was services to persons with Alzheimer's disease and their families. The funding, which began in July, 1986, allowed the Chapter to implement the In-Home Services component of the Community Services Program by employing two Respite Workers to relieve family caregivers for short periods of time on a weekly basis.

Other: Two proposals are currently pending to further develop the Training Center component of the Program. These include an application to a local foundation for a full-time staff person devoted entirely to training, and an application to the National Institute of Mental Health via the State Division of Mental Health to train respite care workers in the skills of caring for Alzheimer's patients. This 3 year grant, if approved, would allow the Chapter to develop a Respite Care Registry with these trained workers and match them with families needing assistance. The program is designed to offer a 3 week training period, with a combination of classroom instruction and practicum in the Day Center. The Day Center will be used as a clinical environment for the trainees to develop and demonstrate "hands-on" skills in caring for patients.

B. Search for Facility

The fund-raising consultant suggested that a location for a Day Care Center needed to be found before funds could successfully be raised. Therefore, the Committee began to search the community for possible buildings. Guidelines (Attachment B) were developed for the appropriate type of facility, and were circulated among Board members and friends of the Chapter. The guidelines included particulars about geographic location, physical plant, space requirements, and cost.

Many visits were made throughout the community, and facilities considered were a free-standing recreational building in a public housing project, a private residence, an unused area of a general hospital, a building previously used as a children's hospital that had been purchased by a community group, a commercial building and space in churches.

The effort was met with many frustrations, as problems associated with each location were encountered. Proposals to use at least two of the facilities were made, but were rejected by the governing bodies. Although the reasons were not delineated, it was suspected that the relative newness of ADRDA as an operating agency, and some suspicion and lack of understanding of the nature of Alzheimer's disease patients contributed to these rejections.

The search took place over a 5-6 month period, but finally in the fall of 1984, space was identified at the Brookhaven Christian Church in north Atlanta. Provisions of a lease were negotiated with the Church, with occupancy arranged for January 1, 1985.

The entire lower level of the Church was made available to ADRDA for the Day Care Center. This included a large fellowship hall, with adjacent office space on one side, and a kitchen and bathrooms on the other. (Rough floor plan drawing - Attachment C). The amount of space available was 2,000 square feet, excluding kitchen and bathrooms. The major concerns with the space were the cost ($15,000 annual rent), and the lack of a secure outdoor area. However, it was decided that the total momentum of the program would be lost if the location was not determined and the fund-raising effort further delayed.

In early 1986, plans were made to co-locate the Chapter's headquarters office and Day Center in a single location. The facility, the Northwoods Presbyterian Church, was able to offer a plan which tripled the amount of space available for the Chapter Office and doubled the amount for the Day Center. The amount of rent was less, and a fenced-in outdoor area was arranged. (Attachment R - Northwoods Floor Plan). The Church is also very interested and supportive of ADRDA, and requested and received funds from the Presbytery of Georgia to make the necessary renovations and install the fence. The Chapter Office moved to the new facility the first week of March, and the Day Center is scheduled to move the first week of April, 1986.

C. Recruitment and Selection of Staff

The original concept for staffing the program with a team of a social worker, registered nurse, and occupational therapist, was discarded after further consideration because of the high cost involved in the employment of such personnel, and the lack of administrative accountability. A plan was substituted which called for a Community Services Director who would have general oversight of the Program and be under the supervision of the ADRDA Executive

Director; a Clinical Coordinator, responsible for client assessments and the coordination of the Respite Program; and a Day Center Program Manager, accountable for daily activities and programming at the Day Center. Following the employment of these persons, and as the program grew in size, two Program Assistants were added. The two Respite Workers were added following receiving Title III funds in July, 1985.

Advertising for the position of Community Services Director began in late November, 1984, with ads placed in the local paper. The ad described the position, and sought individuals with degrees in social work, nursing, gerontology, psychology, or related areas. Resumes were received from twenty applicants, and from this number four persons were selected to be interviewed. The scarcity of applicants with a background that included experience with Alzheimer's disease patients, adult day care or in-home services was apparent. The person who was considered the most qualified was employed, effective February 1, 1985. This individual held a Master of Social Work degree and had previous experience in programs serving the elderly.

Following the employment of the Community Services Director, recruitment began for the positions of Clinical Coordinator and Day Center Program Manager. Again, the applicant pool showed a dearth of persons with relevant background and experiences. Perhaps, too, the positions did not interest some applicants because of the relatively low salary levels, lack of fringe benefits, and the perceived lack of job security.

In March, 1985, selections for these two positions were made. Fortunately, the persons chosen, although not possessing work experience in adult day care or with Alzheimer's patients, did have other characteristics desirable for the job. The person selected as Clinical Coordinator held both a B.S. in Nursing and a Master of Social Work degree. The Day Center Program Manager position was filled with an individual with a B.A. degree in psychology, and whose practical experience with Alzheimer's came as a caregiver to her mother who is a victim of the disease.

As the program grew closer to initiation, problems were encountered with the Community Services Director. At the root of these were her lack of experience with Alzheimer's patients, and her inability to share the same level of commitment to the program as that expressed by the Board of Directors and Executive Director. As a result, she left the Program after the first week of program operation.

Following this action, it was decided not to fill the position, and to spread the program duties between the Executive Director, the Clinical Coordinator, and the Day Center Program Manager. The funds used for this position were spent in an earlier than anticipated employment of Program Assistants.

At the end of 1985 a decision was made to again recruit for the position of Community Services Coordinator because of the increasing work loads of all other staff and the availability of funds to support the position. The position was filled effective 3/1/86 with a well-qualified candidate holding a Master of Social Work degree. A registered nurse is being recruited to fill the position of Clinical Coordinator on a part-time basis.

D. Preparation Steps for Initiation of Program

Relationships with other community agencies were underway prior to the opening of the Center. One key relationship was with the county-based aging services agency in the county in which the Center was located. ADRDA arranged with this agency, the DeKalb Community Council on Aging (DCCOA) for the daily delivery of meal service to the Center through a subcontract with its vendor, Servomation. ADRDA reimburses DCCOA for the cost of the meals on a monthly basis.

Participants in the program were recruited primarily through publicity and announcements made by the Chapter in newsletters, support group meetings, information packets, and word-of-mouth by Chapter members.

Policies and Procedures for both the Day Center and Respite Program were developed which outlined the purpose of the programs, and other pertinent information (Attachment E).

Furniture appropriate for a Day Care Center was selected from a provider of furnishings for institutional settings. The intent for the area to look non-institutional was maintained, with the selection of chairs and a sofa which were functional as well as attractive. Donations were received of other chairs and sofas, and the Church loaned the use of a piano, which has proved to be a very necessary requirement.

Obtaining liability insurance was somewhat difficult, and more expensive than had been anticipated. According to the insurance agency, only two companies in the U.S. would insure adult day care centers. An umbrella policy, general and employee liability amounting to $1,500,000 coverage was purchased for an annual cost of $1,600.

Coverage for malpractice for the registered nurse, workmen's compensation, and unemployment insurance was also purchased. As a requirement of the Title III grant, surety bonds for the Executive Director, Administrative Coordinator, and Treasurer were purchased. The total amount spent for all these policies was $2,165.

III. DESCRIPTION OF COMMUNITY SERVICES PROGRAM

A. Overview

The Day Center offers a protective environment for persons with Alzheimer's and related dementias. The program offers mentally and physically stimulating activities which are geared for persons who need support and supervision during the daytime hours.

Hours for the Center program are from 8:00 a.m. to 5:30 p.m. The current daily maximum capacity of the Center is 15 persons.

B. Admission Policies and Procedures

Eligibility for the program is based on the following:

* Diagnosis of Alzheimer's disease or a related dementia.
* Staff evaluation that the individual's behavior is compatible with the group setting and can be managed by staff.

The application process is initiated by a family member's request. A simple Application Form and Medical Examination Statement (Attachment F) are mailed to the applicant. After these forms have been completed, an interview in the home is scheduled. In some instances, the family member will request a time to visit the Center before a decision is made to apply.

During the interview in the home, the determination of the fee amount is made and agreement is reached on the number of days of attendance. A policy was made to require at least two days per week of Center attendance per participant.

Fees are requested one week in advance. Adjustments may be made for vacations or other periods of absence if one week's notice is given. Persons who attend on a regular weekly basis are responsible for payment of missed days due to illness or other personal reasons. Since Older Americans Act funds are used to provide primary support for the Respite Program, fees are not charged. Families are encouraged to make voluntary contributions. The same sliding fee scale is used as a suggested contribution scale.

While it is too early in the development of the Center to have developed a comprehensive prediction analysis of applicants that would be likely to work out in the Center, certain "hunches" can be applied. The factors which contribute to the "hunches" are: (1) on the part of the applicant: general good health and mobility, "middle" stages of the disease, continent most of the time, independent with supervision in most activities of daily living, absence of bizarre or aggressive behavior; and (2) on the part of the caregiver: a willingness to "let go", and cooperate with the Center staff in contributing to the patient's adjustment.

Most applications to the Program have been appropriate, and the number of rejections by the staff during the application process has been very limited. In some instances families may request respite care because they are not aware of the Day Center, or do not think a group setting would benefit the patient. During the application process, information and education can be provided which helps the family decide upon the Day Center.

C. The Physical Environment

The large open room available in the lower level of the Brookhaven Church (Layout - Attachment C) has been a very workable one for the Center. This has the advantages of providing immediate observational capabilities for the staff, and giving participants the freedom to walk around as needed. The arrangement into smaller sections with the use of dividers gives the space a more home-like feeling. These sections are referred to with home-like names; such as Living Room (area with sofa, chairs, and TV set), Dining Room (tables and chairs for lunch and snacks).

The open space, in addition to giving room for freedom of movement, also provides the space for group activities, exercises, etc. Hazards, such as footstools and small tables, have been removed. The floor is vinyl tile, which makes for easy clean-up when spills or incontinence occur.

The area is well-lit which promotes a feeling of warmth, and the large windows provide a view to a natural outdoor area. The participants enjoyed planting flowers in this small area during the summer, and many felt a part of watching them grow and bloom. The windows serve as points of distraction, also, for the parking lot can be viewed.

The actual amount of square footage available in the large room is 107 square feel per person (for 15 participants). This is a minimum amount for Alzheimer's patients.

The major deficit in the physicial environment is the secure outdoor area which is accessible from inside. Ideally, such a space would include attractive and/or natural barriers, with sufficient space for exercising, gardening, and sitting. The ground surface should be free of obstacles and uneven surfaces. Fortunately, in the new Northwoods space, this need will be met.

A coat rack is available, with a label for each person's coat and other apparrel. This rack is away from the doors, but in the main room. It would be preferable to have it out of sight, as coats are a reminder for going home.

The small bathroom space in the Brookhaven church has been a problem, but will be improved upon the move to Northwoods. The new space has a larger area to provide space to help participants change clothes as needed, to help wash and clean persons who are incontinent, and to have cabinets to hold supplies and extra clothes. The bathroom is close to the main activity area, which is a necessity.

The kitchen is used for preparing snacks and heating the noon meal which is delivered to the Center by the vendor each day. The kitchen is also utilized for cooking activities. These activities are enjoyed especially by women who have received pleasure from preparing food in the past. Participants also take part in meal clean-up, and are supervised by staff during this exercise. A separate refrigerator and cabinet space reduce confusion with the church's property.

D. Description of Day Center Activities

Structure in the daily program is a necessity because of the nature of Alzheimer's disease, Although variety is enjoyed in the type of activity, the same routine - the same kind of activity occuring at the same time each day is beneficial.

The atmosphere in which the activities take place is important. A positive, caring, informal, respectful attitude is projected by the staff which helps each participant feel enjoyment from the day.

The regular schedule is as follows:

8:00 - 10:00	Arrival and Orientation to Center Coffee and Daily Newspaper
10:00 - 10:30	Range-of-Motion Exercises
10:30 - 11:00	Activities with a Soft Ball
11:00 - 11:30	Snack and Personal Care
11:30 - 12:00	Outdoor Walk
12:00 - 12:30	Group Discussion
12:30 - 1:00	Free Time or Catch-Up Prepare for lunch
1:00 - 2:00	Lunch and Clean-Up Personal Care
2:00 - 2:30	Outdoor Walk
2:30 - 3:30	Varied Group Activities
3:30 - 4:00	Snack and Personal Care
4:00 - 4:30	Prepare for Departure
4:30 - 5:30	Free Time Departure

Arrival: The participant's arrival at the Center is a very key time for both the person and the caregiver. This time provides the first opportunity for staff to welcome the participant, and begin to convey the feeling of warmth that is an essential ingredient in the Program. It is also important to caregivers that their relatives feel at ease, and comfortable with being at the Center.

The group arrival of those persons who ride on one of the buses presents a difficult situation. Giving as much attention is difficult because there are more participants arriving at the same time. Two staff members usually help with the bus arrival to compensate for the briefer time.

Morning Orientation: Through informal conversations by staff with participants, orientation to time and place is accomplished. This is usually done over coffee and casual one-to-one discussions about the particulars of each individual's situation. Participants arrive at staggered times, but most are present by 10:00 a.m.

Exercises: The Exercise Program provides several physical and social benefits. The Center has developed twenty-five or more exercises which use all muscle groups and joints. (Attachment G). Exercises are continued with the use of a soft ball which is thrown and kicked as a soccer ball.

Snacks and Mealtimes: The traditional social significance associated with eating is also important to Alzheimer's patients. Mealtime is also an occasion which requires heavy staff supervision. Many participants need assistance with cutting food, getting started with the eating process, and observation to assure that inappropriate behavior does not occur. A sufficient amount of time is allowed so that participants do not feel rushed and can eat at their own rates of speed.

Outdoor Walking: Walking can be a time for socialization and developing one-to-one relationships with staff and volunteers in addition to the exercise benefits. Being in the outdoors relieves the "hemmed in" feeling experienced by some participants. Walking seems to have positive benefits in reducing anxiety, especialy after mealtimes. A danger which can be present is that even when escorted, some Alzheimer's patients can sense the opportunity to "gain freedom" and attempt to leave the premises.

Arts and Crafts: This popular activity, a mainstay of traditional senior centers, must be adapted appropriately for an Alzheimer's Center. Crafts which involve learning new skills are not effective, and even familiar activities can be frustrating to individuals who no longer have the fine motor skills needed. The most successful crafts have been those which can be associated with having a purpose, such as making holiday decorations, rather than an activity which could be considered frivolous. Cooking has proved to be very enjoyable if kept on a simple level. Making a cake or pie is an activity which is familiar, creative, purposeful, and provides an immediate reward - eating.

Gardening meets the same criteria as cooking, because it has a purpose and is familiar and enjoyable. The reward as far as the product is less immediate, but noting the growth of flowers and vegetables creates daily conversation and observation. Providing the daily care - watering, weeding, picking - has been a constructive activity.

Modified Games, such as indoor golf and bowling, can be useful as group activities because they provide opportunities for momentary pleasures and do not require decision-making.

Music is the activity which is the most universally enjoyable, probably because it is the most familiar and stimulates pleasant memories. Familiar songs, including hymns, are well received by even the most impaired individuals.

Videotapes of classic movies and vintage TV programs can provide a worthwhile afternoon's activity. Familiar faces, such as "Ozzie and Harriett" and "Jack Benny" stimulate memories of the past and offer understandable humor and comedy situations.

Departure time can be the most difficult time of the day for participants who are the last to leave, and for staff who must deal with repeated questions about being picked up. During the last period of time of the day when the departure process has started, staff members can give more individual attention to the remaining participants. Activities which can distract the person from thinking about being picked up are the most productive.

Although group activities and stimulation through social contact with peers is the emphasis of the Center program, the importance of the expression of individuality should be stressed. While the majority of the participants enjoy the group activities, allowance is made within the structure of the Center for non-participation, also. The uniqueness of each person is recognized and respected, and ways are found for each to feel a part of the life and family of the Center.

E. Role of Volunteers

Volunteers play key roles in the Center in providing the individual attention and caring needed by the participants. Volunteers have been recruited for two general job descriptions: (1) to assist the staff in conducting program activities and (2) to provide special services.

In the first role, volunteers help participants in the performance of activities, with personal care, and relate to them as companions and friends. These persons come to the Center on a regular weekly basis at a scheduled time, and spend an average of 3 hours each week performing their duties. There are currently a total of 17 volunteers in this category.

The special services category of volunteer performs a variety of duties which enhance the work of the Center. Included in this would be individuals who provide entertainment on a periodic basis, do secretarial work, or handle shopping chores. Others who cannot work a regular schedule are called on a "contingent" basis when special needs arise. Eight volunteers fall in this category at the present time.

The Chapter has been the primary source of recruitment, with over half of the volunteers recruited coming from Chapter membership, or others whom members have individually solicited. Chapter volunteers bring a special interest and contribution to the Center, as many are former caregivers whose relatives are now deceased. Others, whose Alzheimer's family members live in other cities or states, use this volunteer opportunity to contribute to other Alzheimer's patients when they cannot assist their own relatives because of the distance.

Other sources of volunteer recruitment have been public service announcements in newspapers and on radio, newsletters of other organizations, and through newspaper publicity given to the Center.

Each volunteer has an initial interview with the Program Manager, followed by a training and orientation session. Ongoing supervision is provided "on-the-job" with the Program Manager and other staff giving interpretation of behavior and making suggestions as needs arise.

F. Health Related Services

The goal of the health services program is to help the person with Alzheimer's maintain the highest level possible of physical well-being. Beginning with the information presented on the Medical Examination Form completed by the participant's physician, the health status of each person is monitored by the Clinical Coordinator, a registered nurse. A Care Plan is developed and discussed with at staff meetings so that each staff member is aware of the general health condition of each individual, and can be alert to potential problems. When questions arise, the Clinical Coordinator discusses problems with the responsible family caregiver and makes suggestions on possible solutions.

The question of administering medications has arisen, but has presented problems. The staff person who is a registered nurse also makes initial and on-going assessments and is not physically present at the Center all day to monitor the potential side effects. In most cases, however, families can arrange to give medicines while the participant is at home. For the occasional times that pills are given at the Center, the staff gives them at the written request of the family member.

Other health related services which have been provided are giving vitamin shots, and making arrangements for a class of nursing students to give flu shots to all participants whose family members gave permission.

G. Services to Families

The major service to families is the Day Center itself, which relieves the caregiver of the physical care of the participant during the daytime hours. Other services include a monthly support group meeting and individual counseling as needed. Some of the families involved in the Center also attend other Chapter-sponsored support group meetings because of previous contacts and commitments.

The support group offers the recognized benefits of other Alzheimer's support groups - exchange of ideas, awareness that others have similar problems, etc. - but also provides a time for families to hear about their person's activities and participation in the Center. The meetings are times for staff to share these details of daily life at the Center because the participants cannot give them the feedback that is desired.

Offering strategies on day-to-day management problems and other concerns of caregiving is another service given by staff. Families also share their successes at home with staff at the Center.

The service to families is initiated at the time of the assessment when the staff member spends time with the family reviewing the needs of the patient. This assessment interview is the first time many families have had the opportunity to talk on a one-to-one basis with anyone outside the family about the stresses and problems of caring for the person with Alzheimer's disease. Even if the application does not result in Day Center or Respite Care participation, the family has received a worthwhile service.

H. Description of In-Home Respite Program

The In-Home Respite Program, which was initiated in July, 1985, after the receipt of a grant from Title III of the Older Americans Act, allows the resident family caregiver to be absent from the home for three or six hour blocks of time per week.

The Community Services Program employes two workers to provide service in this component of the program. The Workers received classroom training and work experience at the Day Center, and also participated in the Companion/Attendant/Sitter Class offered by the Visiting Nurse Association.

The Worker provides supervision and companionship to the patient during the absence of the caregiver. The duties of the Worker are to:

* Assist with personal care:

    Bathing person in bed, tub, or shower.
    Helping brush teeth, shave or dress.
    Give help with eating.
    Provide toileting assistance.

* Serve meals as planned and prepared by the family.

* Participate in the social and recreational activities of the person, including exercise programs.

* Assist with the transfer and ambulation of the patient.

* Accompany patient to doctor or other appointments.

* Change linens and remove trash as pertains to the needs of the patient.

There are built-in limitations in the fashion in which the Respite Program is structured because the time available to be spent with each family is limited. The service is offered primarily for periods of half day blocks of time per week per family.

Primary users of the Respite Program have been wives caring for husbands with Alzheimer's disease. Of the thirteen families that have used the service to date, 8 have been in this category. Four of the remainder have been daughters as caregivers to mothers. The exception has been one husband caring for a wife.

In general, persons served in the Respite Program have been more impaired and further progressed in the disease process than those persons who use the Day Center. An exception would be the use of Respite Care while waiting for the Day Center. Two persons also use both services.

The contact with the Day Center and the opportunity to be a part of the total staff of the Community Services Program has been an important ingredient in the Program for the Respite Workers. A staff meeting is held weekly with the Respite Workers when cases are discussed and ideas discussed with the Community Services Coordinator. The job of Respite Worker can be lonely, and the contact with other staff is essential to keep up the morale of the workers. At times when there are no case assignments, the Respite Workers work at the Day Center. This gives additional time for staff supervision and training for the Workers.

During the next fiscal year, the Respite Workers will participate in training programs for similar types of positions. ADRDA consults with home health and companion/sitter agencies in providing training content on Alzheimer's. Heretofore, the training has been conducted by professionals and volunteers. However, ADRDA believes that the Respite Workers can make a valuable contribution by raising the level of consciousness of the trainees about the importance of the direct caregiver role, and relate to trainees on a peer basis.

Another utilization of their services will be made in offering consultation to families and other paid caregivers on a short-term basis in areas of coping with behavior and implementing caregiving strategies. The purpose of this effort is to extend their expertise and expand the number of persons served. It is estimated that 20% of their time will be spent in this type of service.

I. Characteristics of Participants

A total of 60 persons and 60+ caregivers (120+ total) received assistance in the Community Services Program during the first nine months of the program. Participants have ranged in age from 52 to 96, with the majority (63%) being over the age of 75.

Currently in the Center are 6 male participants and 11 female. Five of the six males have wives as their caregivers, and 10 of the eleven females are cared for by their daughters. The remaining male's caregiver is his son, and one female is cared for by her husband. The Respite program currently serves 5 males (all with wives as caregivers) and 2 females (one cared for by her daughter and the other whose caregiver is her husband).

An analysis of the active participants in the Center reveals that

10 have been in the program for six months or more (4 for nine months), 5 for 3-6 months, and 2 for less than 3 months. Seven of the participants fee's are at the lowest level ($5), 6 are in fee levels from 2-7 ($6-12) and 4 in fee levels 8-14 ($16-26.50).

32 persons have participated in the program who are no longer active. An additional seven persons were assessed, but never attended the Center for a variety of reasons, including illness, and resistance on the part of the person with Alzheimer's disease. Of these 32, 16 came for less than one month, 12 from 1-3 months, 3 for 3-6 months, and 1 for almost nine months.

The reasons for discontinuing the program include nursing home placement, illness, difficult behavior, resistance by the person with Alzheimer's disease, and family decisions relating to factors such as whether the distance to the Center was too great, the move of the Alzheimer's patient to live with another relative, the feeling that the person was too sensitive about his or her impairment, to benefit from the program, etc. Four persons also have died since leaving the program.

Details on all the above figures are contained in Attachment H.

J. Benefits to Participants and Families

To help evaluate the effectiveness of the program for participants and family members, the immediate caregivers of persons who had attended the Center on a regular basis for three months or more were asked to give their comments on the program. The following points were made concerning the benefits to the participants:

(1) Better sleeping habits at night, and less napping and

sleeping in the day.

(2) An improved sense of self-worth and self-esteem, stemming from a sense of purpose. Participation in the Center allows for a more "normal" life experience than staying at home all day alone or with a caregiver and provides the participant with a reason to get up in the mornings.

(3) The structured day benefits the person with Alzheimer's disease. Caregivers find that replicating a similar structure and routine in the family setting is difficult.

(4) Persons who have been depressed and withdrawn at home become more outgoing as a result of Center participation.

(5) The opportunity for peer contacts and socialization is helpful to the participant, and also pleasing to the caregiver. The majority of the women in the Center live with their daughters and families and have no other outlets for relationships with persons of their own generation.

(6) Several families reported decreased agitation and restlessness at home, that dispositions were improved, and that the person was more cooperative as a result.

(7) Two caregivers stated that their husbands were "more alert and interested in the world, and spoke more intelligibly."

(8) Several caregivers said that the participant was "happier" and "has a good time" at the Center. Others stated "she looks forward to the activities and social contact" and "she says that she has enjoyed her day when I ask her each time I pick her up at the Center. She can't remember what she did or what she had for lunch, but she does seem to enjoy herself."

The benefits to caregivers that were commented on by family members were:

(1) Relief from the duties of caregiving - the actual physical care plus the stress and strain.

(2) The relief from worry about safety and loneliness. Statements by working caregivers were "My mind is free to concentrate on my work," and "The Center gives me peace of mind.

(3) For those non-working caregivers, the Center also provides time to pursue normal activities and undertake other pursuits. One caregiver returned to college to prepare for the time she must support herself, and others have rejoined civic groups, and find more time for other members of their families. "Having two days a week to take care of personal business, shopping, etc. has been a god-send to me after twelve years of caring for my mother."

(4) Many caregivers reported being relieved from guilt about the care of their relatives, and being pleased that their loved ones experienced enjoyment from the Center. "It gives me a great deal of relief from the nagging guilt that I have experienced after having brought her up here to live with me and my family and taking her away from her friends and her sisters - her peers. Now she has "peers" to chat with and doesn't have to sit home all day with a sitter."

K. Use of Program for Training and Education

The potential for this dimension of the Community Services Program is only beginning to be realized. Already the Day Center has served as the training site for the Respite Workers and staff in the Center.

There continue to be numerous requests to visit the Center and learn more about its services from several non-profit and for-profit agencies desiring to expand their programs to Alzheimer's victims and their families. Because of the demands that these types of requests make on the limited staff, the ADRDA Board approved a plan to make a minimal consultation charge for these groups of $50 for non-profit organizations and $100 for proprietary groups. This income helps to compensate for staff time, and produces funds to underwite the program.

If the funding of the Training component materializes with the proposals submitted to funding sources, the original concept of the Community Services Program will be implemented. The Day Center is an ideal resource for the training of students from a wide variety of disciplines, in-home respite workers, nursing home personnel, volunteers and other staff who care for Alzheimer's patients.

L. Relationships with Community Agencies

ADRDA has been able to make arrangements with other service providers in the community to bring additional resources to the program and to increase the services. These include:

DeKalb Community Council on Aging (DCCOA). As previously described, the noon meal is supplied through this agency. Transportation has also been provided.

MARTA. (Metropolitan Atlanta Rapid Transit Authority). Six participants are transported through one route in DeKalb County in a special handicapped-access van. Families pay $1 each way for this service.

Senior Citizen Services of Metro Atlanta, Inc. Transportation for income-eligible participants (currently two persons) living in Fulton County is being furnished.

Emory University School of Nursing. One graduate student in gerontological nursing was placed in 1985. Other student placements are pending.

Oglethorpe University. Four students have done volunteer work. Discussions are underway to involve students from the fields of psychology, sociology, and liberal arts as a part of their curricula.

University of Georgia. One student from the undergraduate program of family studies completed a field placement during 1985.

Atlanta Community Food Bank. Through this non-profit community organization, food donated by wholesalers and other resources, can be purchased by other non-profit organizations for $.10 per pound.

M. Program as Model for Statewide Program

Probably the most significant impact of the Community Services Program is the fact of its existence which affirms that such a program is viable and constitutes a workable service to Alzheimer's patients. The State Study Committee on Alzheimer's Disease, which met from July-December, 1985, gives high priority to the funding of day care centers. Although only half of the requested state appropriation was approved for FY87, one additional Day Center will be initiated and two

Respite programs will be started. The Committee Report also calls for the establishment of 6 additional centers in the following year.

N. Ongoing Funding Resources

Private community support from foundations, corporations, trusts, and community and civic clubs has constituted the majority of funding for the Community Services Program. However, ADRDA Chapter members also generously supported the service with their contributions. The third source of funds was from the users of the service with fees based on the sliding fee scale. An analysis of these sources is as follows:

	Amount	%
Community	82,851	63
Members	20,166	16
Fees	16,506	13
Title III	7,093	5
Interest	3,411	3
	130,027	100

While the Fund-Raising Committee of the ADRDA Board continues to pursue contributions from the private sector, public funding resources will continue to be utilized in 1986 as they become available.

(1) The Title III grant has been approved in the amount of $22,395 for FY87.

(2) The Community Care Services Program which uses Medicaid funds to support services for those older persons who are nursing

home bound. The Day Center was approved as a Provider in December, 1985, and is currently processing referrals. The rate of reimbursement approved was $34.88 per day.

(3) Approval has been given to receive USDA reimbursement for meals served at the Center. Since ADRDA is under contract with the Atlanta Regional Commision which administers the Title III congregate meals program and the meals delivered to the Day Center meet the requirements for Title III meals, approval was granted for a $.53 per meal reimbursement.

(4) ADRDA will receive a share of the state appropriation of $187,000 to fund the current program and begin another Center in a different area of Atlanta. The decision on the allocation of the appropriation has not yet been made by the State Office of Aging.

P. Impact of Publicity on Program

The major newspaper article which appeared in The Atlanta Constitution in October, 1985 focused much attention on the Center. (Attachment J). Entitled "Finding Happiness from Hour to Hour", the account gave a positive description of the program, and encouraged numerous applications from families who did not know about the Center. Also recruited were volunteers and other media interest.

Following this article, the Cable News Network filmed the program which was seen nationally. In November, WSB-TV also filmed the Center and interviewed caregivers for an evening newscast which was shown prior to the Chapter's Community Awareness Breakfast.

Q. Administrative Needs

The administration of the Program has been somewhat complicated by the fact that the Center and the Chapter Office have been in two different locations, some 6 miles apart. This problem will be remedied with the co-location in the same facility. The administrative work of the program includes (1) recording of fees and contributions; (2) data on participants and families; and (3) payroll, personnel, and expense records. These administrative areas of the Program are supervised by the Chapter's Administrative Coordinator.

The Executive Director assumes the responsibility for (1) monthly reporting to the Atlanta Regional Commission on the Title III expenditures and services; (2) submission of applications for grants; (3) development of reports related to financial areas and statistical information about participants; and (4) overall program supervision.

A description of the administrative areas is as follows:

(1) Recording of fees and contributions. At the time of acceptance of the participant, the Community Services Coordinator submits an Information Sheet (Attachment K) to the Chapter Office. This sheet is filed alphabetically by the name of the participant. Day Center and Respite persons are separately identified. Center attendance and fees and contributions are noted on the Information Sheet. The Day Center Program Manager keeps a daily attendance record, and the information from this record is transmitted weekly to the Chapter Office. Caregivers are provided with a supply of vouchers (Attachment L) which are designed to accompany the checks for fees and contributions. Changes in fees, schedule, or termination, etc., is sent from the Center to the office, as needed to keep records current.

(2) A data file is kept for each person assessed for the Program. This file is used for mailings, and for developing various types of analyses. Each data file includes the following information: name of participant, name of caregiver, address of caregiver, telephone number, date of birth of participant, date of diagnosis, date of entry in program, relationship of caregiver, service provided (day care or in-home respite), fee level, and date and reason for discontinuance. The data file is limited by the present software on the Chapter's computer. When another system is purchased which will have a larger data base, additional details can be kept.

(3) Time sheets are kept for each employee for payroll purposes. The ADRDA Treasurer writes the payroll checks, keeps records of expenditures, and submits monthly reports on income and expenses. A record of each employee's leave status is kept on record in the Chapter Office.

(4) Other forms are included in Attachments M-Q.

R. Evaluation of Strengths and Weaknesses

The strengths of the program are that it has been able to involve a number of excellent staff members at all levels of service provision with a sincere interest and commitment to the well-being of persons with Alzheimer's disease and their families. Undergirding the staff's work is a dedicated ADRDA Board of Directors who have been willing to take the risks involved in launching such a major effort.

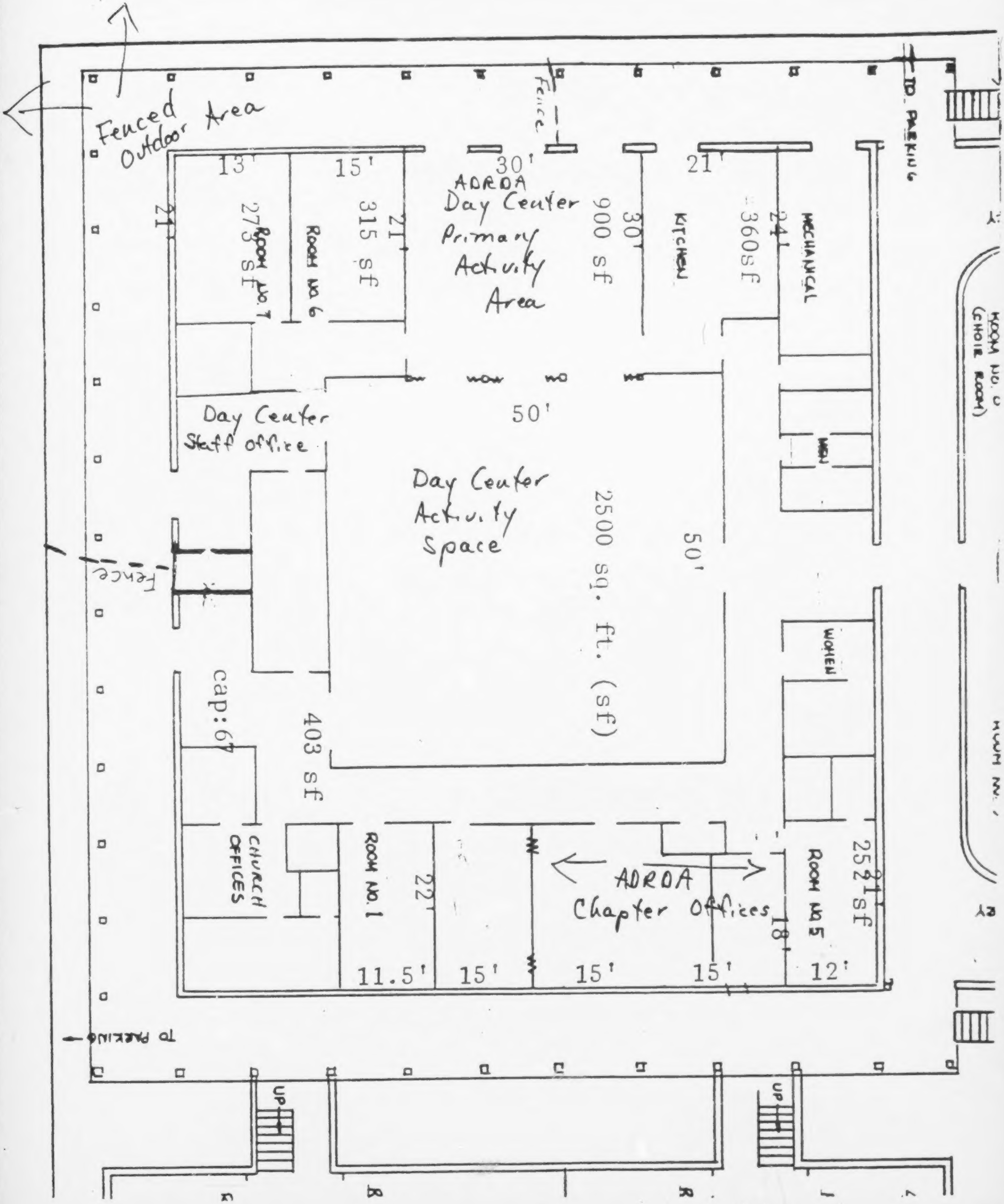
The involvement of families whose relatives are participants in the Program has also been rewarding. They have spoken on behalf of ADRDA in numerous hearings on aging services, and have testified in television interviews and before legislative bodies. This type of advocacy effort has emphasized the effectiveness of this service as a support to families and has increased the likelihood that other Centers will be developed and funded.

The Center has reached capacity level in less than one year. This has been an accomplishment, because the eight other adult day care centers in the metro area are not at maximum levels. All of these Centers have operated for much longer periods of time. The reasons for reaching capacity levels could be surmised as the following:

* The Center is administered by an ADRDA Chapter which enjoys the confidence of families, and is in contact with the target group of potential users of the service. Also, it is the only Center in the metro area which offers a specialized service to Alzheimer's patients.
* The Center has projected a positive image, and is educating families that the program benefits the patient as well as the caregiver.
* The sliding fee scale makes the program affordable.
* The Center meets a well documented need.

The major weakness is the lack of a secure continuing funding base which creates anxieties about the future for families, staff, and ADRDA Board members, and limits expansion into other desired areas for full implementation of the concept. Another year of funding development with additional support from the public sector will help to remedy this weakness.

NORTHWOODS CHURCH Attachment R



Fenced Outdoor Area
Fence
TO PARKING
13'
15'
30'
21'
ADRDA Day Center Primary Activity Area
900 sf
30'
KITCHEN
24'
360sf
MECHANICAL
21
273 sf
ROOM NO. 7
ROOM NO. 6
315 sf
21'
ROOM NO. 0 (CHOIR ROOM)
50'
Day Center Staff Office
MEN
Day Center Activity Space
2500 sq. ft. (sf)
50'
Fence
WOMEN
ROOM NO.
cap:67
403 sf
CHURCH OFFICES
ROOM NO. 1
22'
ADRDA Chapter Offices
ROOM NO. 5
252 sf
21'
18'
11.5'
15'
15'
15'
12'
TO PARKING
UP
UP

8/

Attachment A

ADRDA COMMUNITY SERVICES PROGRAM FEE/ CONTRIBUTION SCALE

Net Yearly Income	Monthly Income	1&2	3	4	5-	
Up to 5000	0 - 416	5.00	5.00	5.00	5.00	(1)
5001-7000	417 - 583	5.00	5.00	5.00	5.00	(1)
7001-8500	584 - 708	6.00	5.00	5.00	5.00	(2)
8501-10000	709 - 833	6.00	6.00	5.00	5.00	(2)
10001-12000	834 - 1000	8.00	8.00	8.00	7.00	(3)
12001-13000	1001- 1083	9.00	9.00	8.00	8.00	(4)
13001-15500	1084- 1292	10.00	9.00	9.00	8.00	(5)
15501-18500	1293- 1542	11.00	10.00	9.00	9.00	(6)
18501-20000	1543- 1667	12.00	11.00	10.00	10.00	(7)
20001-22000	1668- 1883	16.00	15.00	14.00	14.00	(8)
22001-25000	1884- 2083	18.00	17.00	16.00	15.00	(9)
25001-28000	2084- 2333	20.00	19.00	17.00	16.00	(10)
28001-30000	2334- 2500	21.00	20.00	18.00	17.00	(11)
30001-33000	2501- 2750	22.00	21.00	20.00	18.00	(12)
33001-36000	2751- 3000	*24.00	23.00	21.00	20.00	(13)
36001-40000	3001- 3333	26.50	24.00	23.00	22.00	(14)

(1) Day Care Fee is based on a minimum of (1) 6 hour Program Day. Extra hours are at no additional charge.
Maximum Day Care Cost is $26.50 per day.

(2) Respite Care Worker fee is for (1) 3 hour block of respite care time. For 6 hours (maximum for 1 day), fee would be doubled.
Maximum Respite Care fee per 6 hour day is $42 (*these fees would be over maximum of $42, set at $42). Maximum fee for a 3 hour period of Respite Care is $21.00.

(3) Net Yearly Income should be figured on actual income, assets, and extraordinary expenses for medical care. This Income should be based on IRS criteria or Legal criteria for Dependent or Competence. Therefore, a person who is not classified as a Dependent will use his or her own Income Data to figure fees. A person who is a Dependent should base such fees on Family Income with his or her Income included. The fee structure does include provisions for number of persons in family in such cases (should include patient in count).

Attachment B

DAY CARE CENTER FOR ALZHEIMER PATIENTS

The Atlanta Area ADRDA Chapter has identified a need for additional resources to help Alzheimer's patients and their families when the patients are in the early and middle stages of the disease.

To provide this assistance, the Chapter has developed a plan for a Day Care Center which would have these purposes:

(1) To help the Alzheimer's victim make the most of remaining capabilities by providing activities in a supervised and supportive environment, and

(2) To give support, education, and relief to the family responsible for caring for the relative with the disease.

The Chapter is currently engaged in a search for an appropriate facility in which to house the program. Suggestions and assistance are being solicited from members and friends of the Chapter on possible sites which would be suitable for a Center. The following are the suggested requirements for the Center:

GEOGRAPHIC LOCATION

1st Preference: Within close proximity (5 to 10 mile radius) of Chapter Office.

Accessible to major expressways or arteries.

Inside I-285 within northeast or northwest quadrants.

2nd Preference: Other locations.

PHYSICAL PLANT

1st Preference: Free-standing building of which Center could have exclusive use, and could also be used for other Chapter activities, such as meetings and training.

2nd Preference: Exclusive use of space in building used for other purposes by another group or groups.

3rd Preference: Shared space with another program.

Suggested types of facilities to be considered:

(1) Parks and Recreation Buildings
(2) Houses
(3) Schools
(4) Churches
(5) Office Buildings
(6) Community Centers
(7) Hospitals
(8) Housing Projects

Attachment B
Page 2

SPACE REQUIREMENTS

(1) Barrier-free access.

(2) Ground or first floor level.

(3) Ability to meet zoning requirements.

(4) Total space (excluding halls, kitchen, storage, bathrooms, and offices) to equal 35 square feet of usable space per participant. (The Center is projected to serve 15-20 persons at any one time.)

(5) Two (2) barrier-free bathrooms.

(6) Outdoor area which provides sufficient space for activities and is or can be secured by fences or other barriers.

(7) Kitchen available for light snacks and cooking activities by participants. It is not planned to prepare lunch on site, but to have it catered from an outside source.

(8) Rooms: 1 large activity room
1 smaller room for quiet activities
1 smaller room for resting, sleeping
Office space
Coat and storage area

(9) Sufficient parking space, with area adjacent to Center to provide for safe loading and unloading of passengers.

COST

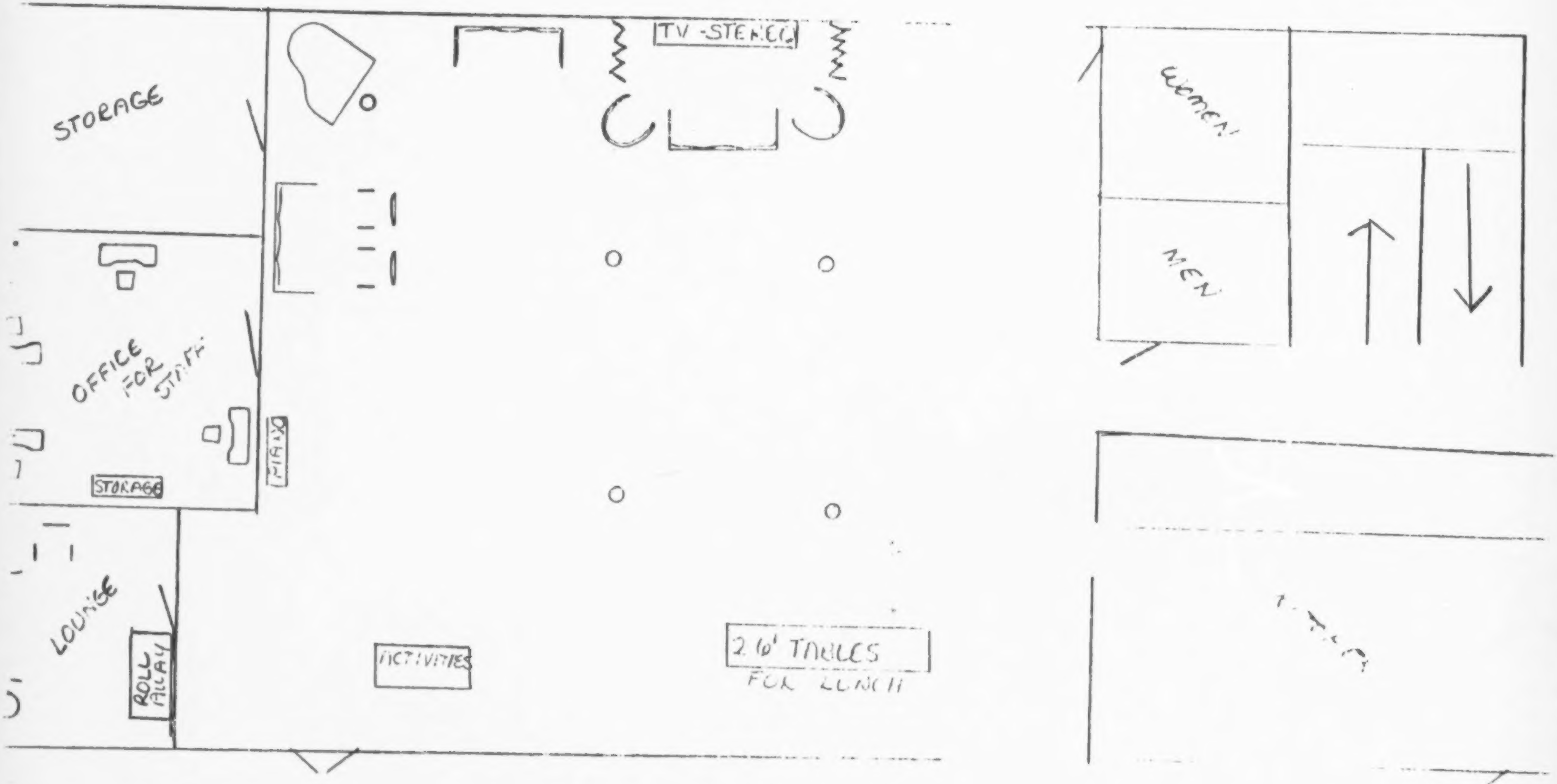
1st Preference: Contributed by community group or individual.

2nd Preference Reasonable cost for monthly rental.

Attachment C

40' x 50' excluding [illegible]

1/3" = 1'


STORAGE
OFFICE FOR STAFF
STORAGE
LOUNGE
ROLL AWAY
PIANO
TV-STEREO
ACTIVITIES
2 6' TABLES FOR LUNCH
WOMEN
MEN

Lower Level

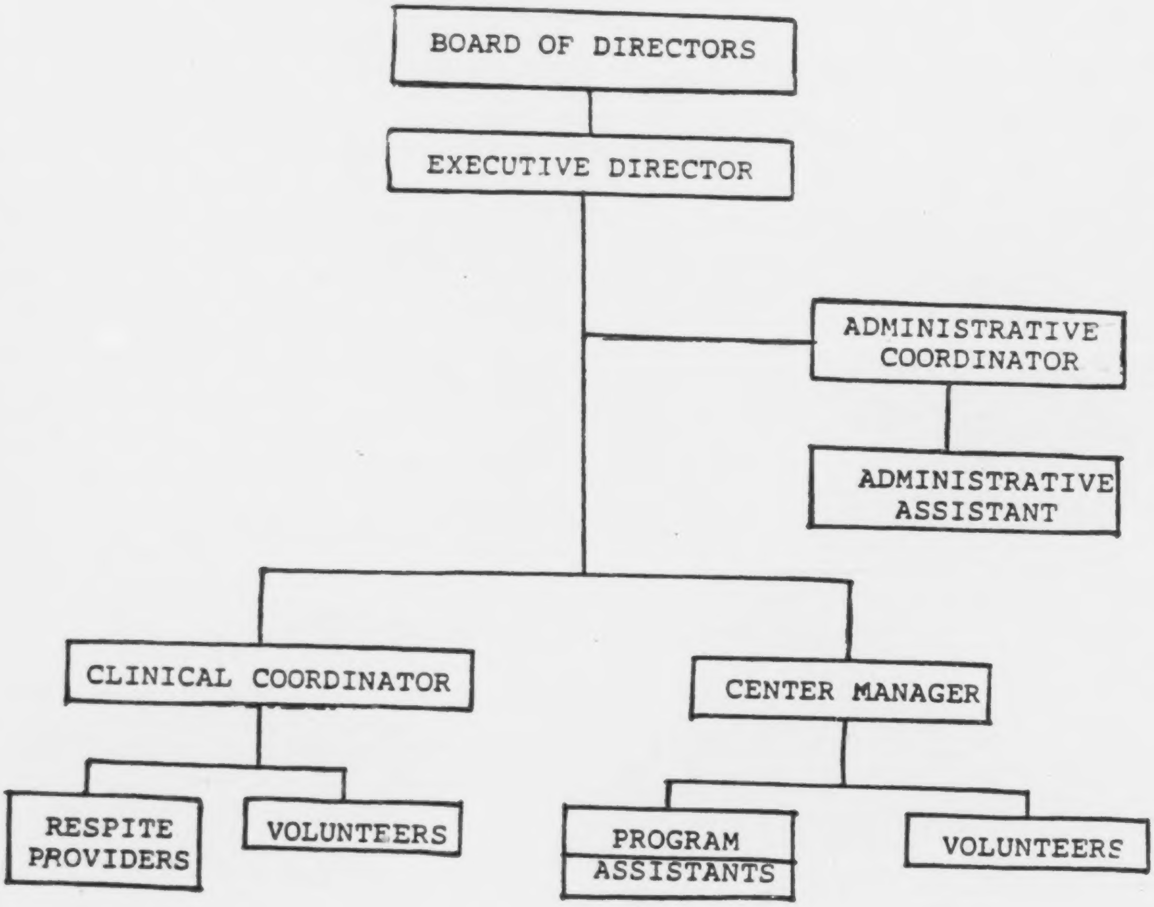
Brookhaven Christian Church

Attachment D

ATLANTA AREA CHAPTER
ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.

ORGANIZATION CHART

NAME OF GOVERNING BODY - BOARD OF DIRECTORS
COMPOSITION - (See attached list)
COMMITTEES OF BOARD - Executive, Nominating, Fund-Raising, Personnel, Autopsy, Education, Support Group Development, Advocacy, Corporate/Foundation Gifts, Awareness/Publicity, and Finance


BOARD OF DIRECTORS
EXECUTIVE DIRECTOR
ADMINISTRATIVE COORDINATOR
ADMINISTRATIVE ASSISTANT
CLINICAL COORDINATOR
CENTER MANAGER
RESPITE PROVIDERS
VOLUNTEERS
PROGRAM ASSISTANTS
VOLUNTEERS

Attachment E

POLICIES AND PROCEDURES

ALZHEIMER'S DAY CENTER

PURPOSE OF PROGRAM

The Center offers a protective, mentally and physically stimulating environment for persons with Alzheimer's or similar conditions which cause memory loss and confusion. Daytime services to participants include:

- Group activities such as music, arts and crafts, games, gardening.
- Exercise program, including range-of-motion and walking.
- Specialized activities, according to needs of participants.
- Monitoring of medical needs and personal care as necessary.
- Group discussion of disease and problems.
- Opportunities for reminiscing.
- Socialization and emphasis on daily living skills.
- Hot lunch, and morning and afternoon snacks.

Also, family caregivers are provided with the following:

- Relief from care of family member during daytime hours.
- Monthly support group.
- Regular updates on participant's health and progress in Center.
- Referral to other appropriate community services.
- Opportunities for information and education about Alzheimer's disease through special sessions, newsletters, and Chapter programs.

ADMISSION REQUIREMENTS

Eligibility for the program is based on the following:

- Diagnosis of Alzheimer's disease or a related dementia.
- Staff evaluation that individual's behavior is compatible with the group setting and can be managed by staff.

Procedures for application include:

- Submission of application form by family.
- Interview in the home by Clinical Coordinator.
- Completion of medical evaluation by physician.
- Provision by family of all appropriate financial and health information to make determination of fee amount and develop plan of care for participant.
- Agreement by Clinical Coordinator and family on number of regular days of Center participation.

Following completion of the above requirements, the Clinical Coordinator will notify family of acceptance into Center within three working days. For persons for whom it is determined that the Alzheimer's Day Center is not appropriate, the Clinical Coordinator will suggest and help to arrange other community services.

Attachment E
Page 2

LEVEL OF PARTICIPATION

The Center's hours are from 8:00 a.m. to 6:00 p.m. Monday through Friday. The minimum amounts of time that a person may participate in the program are as follows:

Daily:	10:00 a.m. to 3:30 p.m.
Weekly:	2 days.

The purpose of this minimum requirement is to allow the participant the optimum opportunity for adjustment to a setting outside the home and realize the benefits of the Center. Because Alzheimer's disease and related disorders diminish the person's abilities to learn new information and become accustomed to new environments, families should allow their relatives a minimum of one month in the program before making a judgment on continued participation.

Maximum amount of time a person may attend the Center is 5 days per week during the total hours of operation.

The caregiver and the Clinical Coordinator will agree upon the hours and days of attendance at the time of acceptance into the program. Consideration of adjustments to this schedule may be initiated at any time by the family. The decision will be based on space available in the program and the needs of the participant.

PAYMENT FOR SERVICES

The fee schedule for the Center is a sliding scale based on the income of the individual and/or spouse, in the case of a married couple. Financial information to determine the fee must be provided at the time of application. The Clinical Coordinator will advise the family of the amount of the daily/weekly fee at the time of acceptance. Families should notify the Clinical Coordinator of any changes to income at any time during the person's participation in the Center.

Fees are payable one week in advance. Checks to the Atlanta Area ADRDA Chapter are the preferred form of payment.

Persons attending on a regular weekly basis are responsible for payment of missed days due to illness or other personal reasons. Adjustments may be made for vacations or other periods of absence if one week's notice is given.

Persons attending the Center for fewer than 5 days will also be responsible for payment of missed days if these fall on regularly scheduled days and it is not possible to reschedule these times in advance.

ADRDA reserves the right to make adjustments to the sliding fee schedule according to the financial needs of the Center.

Fee income represents only a small portion of the operating budget of the Center. The majority of income comes from contributions from

Attachment E
Page 3

individuals and groups in the community. Tax-deductible contributions to the Atlanta Area ADRDA Chapter designated for the Day Center are encouraged from families and friends of program participants.

Relatives of participants are also invited to become members of the Atlanta ADRDA Chapter in order to help support the services which ADRDA provides to families in the metro area, and to receive regular Chapter and National Newsletters which give up-to-date information on Alzheimer's disease and available programs and services.

TRANSPORTATION

Transportation to and from the Center is the responsibility of the family. The Center is working with community agencies, including MARTA, to arrange transportation where needed. In the event arrangements can be worked out, the cost must be reimbursed by the family.

The Center will also help to establish carpooling arrangements when appropriate.

HEALTH AND PERSONAL CARE

The Day Center is a specialized program of care for persons with Alzheimer's disease and related dementias. Primary emphasis is on easing the disability caused by these impairments and maintaining and improving the social and behavioral functioning of each individual. This approach requires close coordination between the Center and the family of each participant.

After admission, an assessment of the individual's health and social needs is completed by the Clinical Coordinator and Center Manager and a plan of care established in consultation with the family. The plan will be reviewed each 60 days, or more often as circumstances warrant.

To assist in maintaining the highest level of functioning for each person, the Center requests that families:

(1) Notify the Clinical Coordinator of any changes in medication or medical treatment following the admission evaluation by the physician.

(2) Dispense medications at home. Exceptions to this are antibiotics prescribed for short periods of time, vitamins, or over-the-counter drugs and tonics which do not require follow-up monitoring. Any medication must arrive at the Center in its original container and be provided on a daily basis.

(3) Provide for yearly physical examinations by primary care physicians.

(4) Supply a clean towel, wash cloth, and underwear to keep at the Center. Each item should be marked with the name of the person to whom it belongs. If the participant has occasional periods of

Attachment E
Page 4

incontinence, the family must provide briefs. Laundering is the responsibility of the family.

(5) Label all outer clothing (coats, sweaters, etc.) and canes, walkers and glasses. Medic-Alert bracelets are also recommended.

DISCHARGE POLICY

Services at the Center will be terminated for the following reasons:

* Increased needs of participant which cannot be met by staff. These could include:

  Uncontrolled combative or abusive behavior.
  Uncontrolled wandering from Center.
  Behavior dangerous to self or other participants.
  Unmanageable incontinence.
  Excessive personal care needs.

* Irregular attendance.

* Non-payment of fees of more than 10 days of service.

* Contagious diseases or infections.

The Day Center will give at least one week's notice of termination, except in the case of contagious diseases or infections which willrequire immediate action by the family. The family will have the right to appeal to the ADRDA Executive Director, 1817 Clifton Road, N.E., Atlanta, GA 30029. An appeal must be delivered in writing within 10 working days after receiving notice of discharge.

The Center staff will assist the family in making alternative arrangements if participation in the Center is no longer feasible.

HOLIDAYS

The Center will observe the following holidays:

* **New Year's Day, or work day nearest same**
* **Birthday of Martin Luther King, Jr.**
* **Memorial Day**
* **Independence Day**
* **Labor Day**
* Thanksgiving Day and the following Friday
* Christmas Day and designated day either before or after

The Center will also close during hazardous driving weather, and will follow the schedule for the DeKalb County School System. Families should follow radio and TV broadcasts for information about closings.

Attachment E
Page 5

AGREEMENT:

These policies have been discussed and I understand my responsibilities and those of the Alzheimer's Day Center. Furthermore, I give permission to the Center to share pertinent information pertaining to the health and social status of my family member with other agencies as necessary.

I also give permission for the Center to take my family member on field trips and outings, with the understanding that I will be notified in advance of any such activity.

REGULAR DAYS OF ATTENDANCE ____________________

FEE ____________________

____
RESPONSIBLE FAMILY MEMBER

____
ADRDA CLINICAL COORDINATOR

____
Date

* *

AMENDMENT ____________________

____________________ Date ____________________

____
RESPONSIBLE FAMILY MEMBER

____
ADRDA CLINICAL COORDINATOR

* *

AMENDMENT ____________________

____________________ Date ____________________

____
RESPONSIBLE FAMILY MEMBER

____
ADRDA CLINICAL COORDINATOR

Attachment E
Page 6

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.
ATLANTA AREA CHAPTER
HOME RESPITE PROGRAM
262-7271

The Atlanta Area Chapter of ADRDA welcomes your application to its Respite Program. This in-home companion service is provided by a responsible, trained, individual under the supervision of a Registered Nurse/Clinical Social Worker.

Definition Home respite is care given by a Respite Provider that allows the resident family caregiver to be absent from the home for three hour blocks of time.

Goals To enhance the quality of life for caregivers of persons with Alzheimer's disease by providing relief to the family for short periods of time.

To offer training and supervision to Respite Providers to assure quality care for Alzheimer's victims and their families.

To provide consultation to families on problems of care and management.

Eligibility Any caregiver of a victim of Alzheimer's disease or a related disorder in the metro Atlanta is eligible to apply for the Home Respite Program. However, because of limited staff and travel time, service to persons beyond a 15 mile radius of the Alzheimer Day Center will depend upon staff availability.

Time The program operates Monday through Friday between the hours of 9:00 a.m. and 5:00 p.m. The amount of time for regularly scheduled respite care in a one week period is either a 3 or 6 hour block of time.

Payment Although there is no charge for this service, the family is encouraged to contribute to the cost. At the time of the family interview, the Clinical Coordinator will discuss the contribution scale, which is based on income. The suggested range for the contribution is from $5.00 to $21.00 for a 3 hour block of time. Envelopes will be left at the home for mailing to the Chapter Office on a weekly basis. Checks may be made payable to ADRDA for the Home Respite Program.

Respite Provider Respite Providers are individuals trained to give supervision and companionship to the person with Alzheimer's disease or a related disorder. Providers will not do housework for the family, but will focus on the needs of the Alzheimer's victim. Providers will not administer medications, but can give reminders as directed by the family. Duties of the Respite Provider

Attachment E
Page 7

- Thanksgiving Day and the following Friday
- Christmas Day and designated day either before or after

The Program also will not be in operation during hazardous driving weather, and will follow the schedule for the DeKalb County School System. Families should follow radio and TV broadcasts for information about closings.

AGREEMENT:

These policies have been discussed and I understand my responsibilities and those of the Alzheimer's Respite Program. Furthermore, I give my permission to the Program to share pertinent information about the health and social status of the family member with other agencies as necessary.

REGULAR TIME OF CARE ______________________________

DUTIES ______________________________

____

____

____

____

____

AMOUNT OF SUGGESTED CONTRIBUTION ______________________________

____
RESPONSIBLE FAMILY MEMBER

____
ADRDA RESPITE PROVIDER

____
ADRDA CLINICAL COORDINATOR

Date ______________________________

7/23/85

Attachment F

Alzheimer's Disease and Related Disorders Association, Inc.
Atlanta Area Chapter on the Wesley Woods Campus
1817 Clifton Road, N.E., Atlanta, Georgia 30029 / Telephone (404) 633-8759

Officers:
President
Marshall C. Anderson
President-Elect
Cathy Von Wood, R.N., M.S.N.
Vice-Presidents
Belle T. Bennett
John J. Dalton
Julian Raynes
Secretary
Georgie M. Booker
Treasurer
C.R. Shoemaker
Executive Director
Carolyn J. French, M.S.W.
Medical Advisor
Herbert R. Karp, M.D.
Board of Directors
Ross Arnold
Virginia Bonner
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Cindy Jaret
Horace Killebrew, Jr.
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Eve B. Levine, M.S.W.
Gretchen E. Maclachlan
Karen Marshall
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Harvey B. Michael, M.S.W.
Henry E. Midura, Sr.
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Ida Rousseau Mukenge, Ph.D.
Phillip Nieburg
Ralph E. Ricketts
Cynthia Ries, ACSW
Martha B. Sanders
Sam Shapiro
Sam J. Sligar, M.Div.
Paula Sparks
Deborah W. Sullivan, ACSW
Phyllis C. Weisser
Kay White
Frank J. Whittington, Ph.D.
Lillian Wright

Dear ADRDA Family Member:

The application packet for the Alzheimer's Community Services Program sponsored by the Atlanta Area ADRDA is attached. Included are the Application, and Medical Examination Form.

If you want to apply for participation in the Program on behalf of your family member, please follow this procedure:

(1) Return the application form.

(2) Arrange for the completion of the Medical Examination Form by the physician who is most aware of the situation and who sees the person for ongoing care. If he or she has any questions, please encourage him or her to contact the Chapter.

The Medical Examination Form must be received before any decision can be made regarding participation in the Program.

After the return of the Application, we will contact you regarding a time for an interview. We will want to discuss the Program with you and your family member.

It will also be necessary to discuss your contribution to the Program. The Chapter Board has established a sliding fee/contribution scale based on the individual or family income (in the case of a married couple.) Please be prepared to discuss this at the time of the interview.

We look forward to meeting you.

Sincerely,

Carolyn French

Carolyn French
Executive Director

A nonprofit, charitable, tax exempt organization dedicated to family support, education and research.

Attachment F
Page 2

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.
ATLANTA AREA CHAPTER COMMUNITY SERVICES PROGRAM

Application

Name ______________________________

Address ______________________________ Phone No. ________

______________________________ Zip Code ________

Date of Birth ______________ Social Security No. ____ - __ - ____

Married _____ Widowed _____ Divorced _____ Single _____ other _____

Does applicant have a diagnosis of Alzheimer's Disease? Yes ____ No ____

If no, what is the diagnosis? ______________________________

What was the approximate date of diagnosis? ______________________________

Does applicant have other health problems? ______________________________

____

____

Does applicant have special needs that should be addressed in the Program? ______________________________

____

____

How is patient cared for now? ______________________________

____

Family Physician ______________________________

Address ______________________________ Phone No. ________

______________________________ Zip Code ________

Name of primary caregiver ______________________________

______________________________ Zip Code ________

Phone No. (Day) ______________ (Eve) ______________

Please Return to: ADRDA Community Services Program
4500 Peachtree Road, N.E.
Atlanta, GA. 30319
(404) 262-7271

RC _____ DC _____

Attachment F
Page 3

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.
ATLANTA AREA CHAPTER COMMUNITY SERVICES PROGRAM

Medical Examination Form

CONFIDENTIAL

This form must be completed and signed by the Applicant's physician and returned to

ADRDA
4500 Peachtree Rd, N.E.
Atlanta, Ga. 30319
(404) 262-7271

The return of this medical form is an essential part of an application to the ADRDA Community Services program.

Name________________________________ Birth Date__________

Address____

________________________________ Zip Code__________

Is there a diagnosis of Alzheimer's Disease? Yes____ No_____

If yes, when was the diagnosis made?__________________

Is there chronic or other illness?____________________

If yes, what is the diagnosis and/or impairment?__________

____

____

____

____

Medications	Dosage	Sig

Attachment 6

ALZHEIMER'S DAY CENTER EXERCISE PROGRAM

This exercise routine is enjoyed daily by participants in the ADRDA Alzheimer's Day Center. The various movements use all muscle groups and joints in the body. Most are done while seated. Each movement should be repeated 10 times unless otherwise indicated. In addition to the physical benefits of the program, the activity helps maintain cognitive levels of functioning by reviewing body parts, counting, identifying left and right, and following directions. While most participants can follow the simple directions, others may need assistance getting started with a movement.

WARM-UPS

FINGER WIGGLE	Wiggle fingers as if typing or playing piano.
HAND SHAKE	Shake both hands vigorously as if trying to get water off.
MAKE FISTS	Close hands to make fists, and open. Repeat rapidly.
PUNCH OUT	Make fists and punch with both arms, as if boxing.
ARM TWIST	Extend both arms down by sides. Then twist both in, then both out. Repeat rapidly.
SHOULDER ROLL	Relax both arms down by sides. Roll shoulders backwards as if shrugging. Roll shoulders forwards and repeat same sequence.

STRETCHING

LADDER CLIMB	Alternately raise each arm as high as possible as if climbing a ladder.
CHICKEN WING	Make fists. Bend arms at elbows and hold up in front of chest, arms parallel to ground. Bring arms back as if attempting to press shoulder blades together.
ARM JERK	Make fists. Rest arms in lap. Raise arms, touching fists to shoulders. Extend arms as if to touch ceiling. Bring arms back down to shoulders. Then, place arms in lap. Repeat 5 times (or count to 20, with each move as 1 count).
HAND CLASP BENDER	Extend arms in front, palms together. Interlace the fingers. Turn arms inside out. Raise arms above head, move to left, right, out in front, then back up, and relax. Repeat 3 times, holding each position about 3 seconds. Keep hands clasped entire time and stretch as much as possible.

Attachment H

PROFILE OF COMMUNITY SERVICE PARTICIPANTS

TOTAL PARTICIPANTS

Current Participants	
Day Center	17*
Respite	4
Discontinued	
Never Attended	7
Day Center	28
Respite	6
Total	60

* 2 also receive Respite Care

Length of Participation	Less than 1 month	1-3 Months	3-6 Months	6-9 Months	9+ Months
Current					
Day Center	1	1	5	6	4
Respite		2	1	1	
Discontinued	23*	12	3	1	
Total	24	15	9	8	4

* Includes 7 persons assessed who never attended

Age	Under 65	65-75	75-85	85+
Current				
Day Center	2	6	6	3
Respite		2	2	
Discontinued	4	8	24	3
Total	6	16	32	6

DX Date	Under 1 Year	1-3 Years	3-5 Years	5-7 Years	Undiag.
Current					
Day Center	3	3	3	2	6
Respite	1	3			
Discontinued	7	22	4	3	2
Total	11	28	7	5	8

Attachment H
Page 2

Caregiver Status	Spouse	Daughter	Son	Other
Current				
Day Center	6	10	1	
Respite	3	1		
Discontinued	17	14	4	4
Total	26	25	5	4

Sex	Male	Female
Current		
Day Center	6	11
Respite	3	1
Discontinued	14	25
Total	23	37

Fee Level	1	2-7	8-14	Undet.
Current				
Day Center	7	6	4	
Respite	2	2	0	
Discontinued	11	17	8	3
Total	20	25	12	3

Discontinuation Reason	
Death	1
Illness	3
Early Stage	3
AD Person Resistant	4
Difficult Behavior	7
Nursing Home Placement	9
Family Decision	12
Total	39

Attachment I

MEMORY AND BEHAVIOR PROBLEM CHECKLIST A

(Please complete as of the time that family member started Day Center)

FREQUENCY RATINGS

0 = never occurred
1 = has occurred, but not in past week
2 = has occurred 1 or 2 times in past week
3 = has occurred 3 to 6 times in past week
4 = occurs daily or more often
7 = would occur, if not supervised by caregiver (eg., wandering except door is locked).
8 = patient never performed this activity

REACTION RATINGS: How much does this bother or upset you when it happens?

0 = not at all
1 = a little
2 = moderately
3 = very much
4 = extremely

BEHAVIORS	FREQUENCY	REACTION
1. Wandering or getting lost	0 1 2 3 4 7	0 1 2 3 4
2. Asking the same question over and over again	0 1 2 3 4	0 1 2 3 4
3. Hiding things (money, jewelry,etc)	0 1 2 3 4	0 1 2 3 4
4. Being suspicious or accusative	0 1 2 3 4	0 1 2 3 4
5. Losing or misplacing things	0 1 2 3 4	0 1 2 3 4
6. Not recognizing familiar people	0 1 2 3 4	0 1 2 3 4
7. Forgetting what day it is	0 1 2 3 4	0 1 2 3 4
8. Starting, but not finishing things	0 1 2 3 4	0 1 2 3 4
9. Destroying property	0 1 2 3 4	0 1 2 3 4
10. Doing things that embarrass you	0 1 2 3 4	0 1 2 3 4
11. Waking you up at night	0 1 2 3 4	0 1 2 3 4
12. Being constantly restless	0 1 2 3 4	0 1 2 3 4
13. Being constantly talkative	0 1 2 3 4	0 1 2 3 4
14. Talking little or not at all	0 1 2 3 4	0 1 2 3 4

Attachment I
Page 2

15. Engaging in behavior that is potentially dangerous to others or self	0	1	2	3	4	7		0	1	2	3	4
16. Reliving situations from the past	0	1	2	3	4			0	1	2	3	4
17. Seeing or hearing things that are not there (hallucinations or illusions)	0	1	2	3	4			0	1	2	3	4
18. Unable or unwilling to dress self (either partly or totally, or inappropriate dress compared to previous standards)	0	1	2	3	4	7		0	1	2	3	4
19. Unable or unwilling to feed self	0	1	2	3	4	7		0	1	2	3	4
20. Unable or unwilling to bathe or shower by self	0	1	2	3	4	7		0	1	2	3	4
21. Unable to put on make-up or shave by self	0	1	2	3	4	7		0	1	2	3	4
22. Incontinent of bowel or bladder	0	1	2	3	4	7		0	1	2	3	4
23. Unable to prepare meals	0	1	2	3	4	7	8	0	1	2	3	4
24. Unable to use the phone	0	1	2	3	4	7		0	1	2	3	4
25. Unable to handle money (e.g., to complete a transaction in a store; do not include being unable to manage finances)	0	1	2	3	4	7		0	1	2	3	4
26. Unable to clean house	0	1	2	3	4	7	8	0	1	2	3	4
27. Unable to shop (to pick out adequate or appropriate foods)	0	1	2	3	4	7	8	0	1	2	3	4
28. Unable to do other simple tasks which he/she used to do (e.g., put away groceries, simple repairs)	0	1	2	3	4	7		0	1	2	3	4
29. Unable to stay alone by self	0	1	2	3	4			0	1	2	3	4
30. Are there any other problems?	0	1	2	3	4			0	1	2	3	4

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Attachment I
Page 3

MEMORY AND BEHAVIOR PROBLEM CHECKLIST B

(Please complete as of current date)

FREQUENCY RATINGS

0 = never occurred
1 = has occurred, but not in past week
2 = has occurred 1 or 2 times in past week
3 = has occurred 3 to 6 times in past week
4 = occurs daily or more often
7 = would occur, if not supervised by caregiver (eg., wandering except door is locked).
8 = patient never performed this activity

REACTION RATINGS: How much does this bother or upset you when it happens?

0 = not at all
1 = a little
2 = moderately
3 = very much
4 = extremely

BEHAVIORS	FREQUENCY	REACTION
1. Wandering or getting lost	0 1 2 3 4 7	0 1 2 3 4
2. Asking the same question over and over again	0 1 2 3 4	0 1 2 3 4
3. Hiding things (money, jewelry,etc)	0 1 2 3 4	0 1 2 3 4
4. Being suspicious or accusative	0 1 2 3 4	0 1 2 3 4
5. Losing or misplacing things	0 1 2 3 4	0 1 2 3 4
6. Not recognizing familiar people	0 1 2 3 4	0 1 2 3 4
7. Forgetting what day it is	0 1 2 3 4	0 1 2 3 4
8. Starting, but not finishing things	0 1 2 3 4	0 1 2 3 4
9. Destroying property	0 1 2 3 4	0 1 2 3 4
10. Doing things that embarrass you	0 1 2 3 4	0 1 2 3 4
11. Waking you up at night	0 1 2 3 4	0 1 2 3 4
12. Being constantly restless	0 1 2 3 4	0 1 2 3 4
13. Being constantly talkative	0 1 2 3 4	0 1 2 3 4
14. Talking little or not at all	0 1 2 3 4	0 1 2 3 4

Attachment I
Page 4

15. Engaging in behavior that is potentially dangerous to others or self	0	1	2	3	4	7		0	1	2	3	4
16. Reliving situations from the past	0	1	2	3	4			0	1	2	3	4
17. Seeing or hearing things that are not there (hallucinations or illusions)	0	1	2	3	4			0	1	2	3	4
18. Unable or unwilling to dress self (either partly or totally, or inappropriate dress compared to previous standards)	0	1	2	3	4	7		0	1	2	3	4
19. Unable or unwilling to feed self	0	1	2	3	4	7		0	1	2	3	4
20. Unable or unwilling to bathe or shower by self	0	1	2	3	4	7		0	1	2	3	4
21. Unable to put on make-up or shave by self	0	1	2	3	4	7		0	1	2	3	4
22. Incontinent of bowel or bladder	0	1	2	3	4	7		0	1	2	3	4
23. Unable to prepare meals	0	1	2	3	4	7	8	0	1	2	3	4
24. Unable to use the phone	0	1	2	3	4	7		0	1	2	3	4
25. Unable to handle money (e.g., to complete a transaction in a store; do not include being unable to manage finances)	0	1	2	3	4	7		0	1	2	3	4
26. Unable to clean house	0	1	2	3	4	7	8	0	1	2	3	4
27. Unable to shop (to pick out adequate or appropriate foods)	0	1	2	3	4	7	8	0	1	2	3	4
28. Unable to do other simple tasks which he/she used to do (e.g., put away groceries, simple repairs)	0	1	2	3	4	7		0	1	2	3	4
29. Unable to stay alone by self	0	1	2	3	4			0	1	2	3	4
30. Are there any other problems?	0	1	2	3	4			0	1	2	3	4

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Attachment I
Page 5

OTHER COMMENTS

Has the Center affected your family member's quality of life? (For example, mood, disposition, cooperation, etc.)

Has your relative's participation in the Center affected your life in any way?

Other comments:

PLEASE ATTACH OTHER SHEETS IF NECESSARY

THE ATLANTA CONSTITUTION, Mon., Oct 7, 1985

Attachment J

LANNA SWINDLER/Staff

Volunteer Charlotte Sturgess watches as Peter Garvin tickles the ivories with a little Gershwin.

LANNA SWINDLER/Staff

[illegible]

Finding happiness from hour to hour

Alzheimer's victims get involved at care center

By Nancy J. White

Staff Writer

It was all in a day's play. They gathered around the piano while Peter Garvin, 77, tickled the ivories with a little Gershwin, a little swing era stuff, and a little "When Irish Eyes Are Smiling."

"Look at her," said one woman, motioning toward her 85-year-old mother smiling and clapping. "She doesn't retain the past or comprehend the present, but here she lives happily hour to hour."

The 10 senior citizens at the Alzheimer's Day Center ate eggs and grits for breakfast, went for a walk.

"Wiggle those fingers. Shake those arms," coaxed program director Jayne Midura, and 20 arms — some with the help of staff — were extended in the air. "Try to relax."

"Relax!" said one white-haired gentleman with a hearty laugh. "How can you relax in this joint?"

"It's true," said Ms. Midura. "This joint's hoppin'."

The "joint," located in the basement of the Brookhaven Christian Church, is the only day-care center in the state specifically for patients of Alzheimer's disease or related disorders, according to Carolyn French, executive director of the Atlanta chapter of the Alzheimer's Disease and Related Disorders Association (ADRDA). Opened in April, the center cares for 10 to 15 senior citizens

Attachment J
Page 2

Center

From Page 1-B

a day. In addition, an at-home care program, called In-Home Respite, was started in July.

But more help may be on the way. The state Department of Human Resources recently sponsored hearings about the nature and extent of Alzheimer's Disease and the need for more resources, such as day-care centers for patients. As part of its next budget request, the DHR has asked the governor for $375,000 to begin a pilot program of four centers to help some of Georgia's 44,000 victims. The privately funded Brookhaven facility — operated by the Atlanta chapter of ADRDA — is serving as a model.

Such programs are intended to make life more enjoyable for victims of a disease that slowly, agonizingly deteriorates the mind. An untreatable disorder with an unknown cause, Alzheimer's usually occurs in people over 65, but can hit as early as 40. Symptoms include memory loss, personality changes and, in later stages, inability to concentrate and to make proper judgments. For instance, a victim may wander off and not remember the way home, forget the names of family members or lose all concept of time.

Eventually, the patient is unable to control bodily functions.

The disease is devastating for the families who must not only watch their loved ones slip away, but also provide constant care. "My nerves were frayed," said Charlotte Sturgess, whose mother lives with her. "I'd follow her around picking up things. You become so confined it's as though you have a 6-month-old baby."

Now that her mother attends the center, she said, she has a chance to go grocery shopping, make telephone calls and lead a more normal family life. "I'm better for her when she comes home," she said.

For some family members, the day-care center means they can work and not worry. "Without the center, I'd be up the creek," said Peachy Horne, a real estate agent. "I'd be taking chances with mother's safety. I can't afford someone to come in full time."

Alene Garvin, whose husband goes to the center, said it has given her a chance to get a part-time job and make some extra money.

The Alzheimer's victims at the center are mainly in the middle stages of the disease. Some think the center is a school. Some say they come to help other people. Some refer to the daughters or wives who care for them as their mothers.

Most are in good shape physically, although some need help going to the bathroom and eating. One man thinks of himself as staff, caring for the plants and constantly sweeping.

"They feel better that they've been involved," said Mrs. French of ADRDA, "and not just sitting at home staring at four walls. They have the same human need for contact as other people."

Mrs. Sturgess said the center has added a new dimension to her mother's life. "She realized I baked a cake today and she was so proud to bring it," said Mrs. Sturgess. "One day she said to me, 'I don't know what I'd do without my family at the school.' "

LANNA SWINDLER/Staff

Charlotte Sturgess helps Worley Field to the breakfast table.

Attachment J
Page 3

For more information

The Alzheimer's Day Center is open from 8 a.m. to 5:30 p.m. five days a week. Patients come from all over the metro area. Some in the Stone Mountain-Decatur area are picked up by a MARTA handicapped van.

A day at the center — or a 3-hour In-Home Respite visit — costs anywhere from $5 to $26.50, depending on what the families can afford.

Clinical coordinator Patti Montgomery said that a few slots are currently open in both the Day Center and In-Home Respite programs. A registered nurse and social worker, Ms. Montgomery interviews Alzheimer's patients in their homes to assess if they are suited for the programs. Call 262-7271.

The Atlanta chapter of the Alzheimer's Disease and Related Disorders Association also sponsors 15 support groups in the metro area for families with Alzheimer's victims and monthly classes on the disease. Call 633-8759.

The staff — four paid members plus volunteers — try to keep everyone stimulated. There are group discussions about childhood memories, snacks and meals during the day, modified golf and bowling, individual chats, and arts and crafts. Recently the staff helped them decorate plastic cups; for hers, one woman chose a pin that said: "I am loved."

A cot is available for resting, but most don't use it. Said clinical coordinator Patti Montgomery: "They want to stay with the group, so they just catnap."

For patients who don't do well in a group, Respite workers make home visits. So far, the at-home program has two workers and about 10 patients.

The center and the at-home visits are seen as intermediate steps. "We hope to keep them involved in life for as long as we can," said Ms. Montgomery, "before they have to go to an institution of some kind."

Standing with his cane by the piano he loves to play, Garvin considered what he liked about coming to the center. "It sounds like a terribly goofy thing to say, but I have never in my life met a finer bunch of people," he said. "I have never met anybody here yet who I didn't love."

ALZHEIMER'S DISEASE COMMUNITY SERVICES PROGRAM

Attachment K

Client Record Information

Name

Caregiver________________ Participant________________

Address________________ Birthdate________________

City, Zip________________ Caregiver relationship________________

Phone (W)________ (H)________ Diagnosis date________________

DC____ RC____ Entry date________ Units____ Fee level____ Daily______ Wkly______

Contribution________

Week Ending	Units Used	Paid	Pay Date	Balance	Week Ending	Units Used	Paid	Pay Date	Balance

Attachment L

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.

COMMUNITY SERVICES PROGRAM

Payment Voucher

1. Partipant's Name ______________________________
2. Amount of Payment ______________________________
3. Covers period from ______________ (date) to ______________ (date)
4. Signature of Caregiver ______________________________

Please make checks payable to ADRDA-CSP, and mail to ADRDA, 1817 Clifton Road NE, Atlanta, Georgia 30029.

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.

COMMUNITY SERVICES PROGRAM

Payment Voucher

1. Partipant's Name ______________________________
2. Amount of Payment ______________________________
3. Covers period from ______________ (date) to ______________ (date)
4. Signature of Caregiver ______________________________

Please make checks payable to ADRDA-CSP, and mail to ADRDA, 1817 Clifton Road NE, Atlanta, Georgia 30029.

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.

COMMUNITY SERVICES PROGRAM

Payment Voucher

1. Partipant's Name ______________________________
2. Amount of Payment ______________________________
3. Covers period from ______________ (date) to ______________ (date)
4. Signature of Caregiver ______________________________

Please make checks payable to ADRDA-CSP, and mail to ADRDA, 1817 Clifton Road NE, Atlanta, Georgia 30029.

Attachment M

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.
ATLANTA AREA CHAPTER COMMUNITY SERVICES PROGRAM
Adult Day Center, 4500 Peachtree Rd., NE, Atlanta GA 30319

Fee Payment Commitment

Date ____________________

Participant's Name ________________________ SS # ____-____-____

Birth Date ____________

Address ______________________________ Phone ____________

______________________________ Zip Code ____________

Caregiver Name ________________________ Day Phone ____________

Address ______________________________ Zip Code ____________

Days at Adult Day Center: Wk __ Mon __ Tues __ Wed __ Thurs __ Fri __

Hours at Adult Day Center ______________________________

Net income as verified:

IRS 1040 Form __________ Other __________ Total __________

I certify that I have read the IRS 1040 Form and other documents and that the income stated is correct.

Daily Fee _____ Weekly Fee _____ ________________________
Staff Signature

Fees are payable weekly in advance on the first day of the week the participant attends the Adult Day Center. Please make checks payable to ADRDA Community Services Program. Families are responsible for payment for the above time unless one week's written notice of expected absence is given.

I certify that the above information is correct and

I agree to payment as described

____
Signature of Family/Guardian

Alzheimer's Day Center

Attachment N

DATE:

SELF-CARE DEFICIT RELATED TO.

GOAL:

INTERVENTIONS:

COMMUNICATIONS:

NUTRITION INTAKE:

ELIMINATION:

REST/MOBILITY:

NAME:

BIRTHDATE:

PHYSICIAN:

ALLERGIES:

MEDICAL DX:

MEDICATIONS

1.

2.

3.

4.

5.

DATE	PROBLEM	GOAL	INTERVENTION

Attachment O

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.
ATLANTA AREA CHAPTER COMMUNITY SERVICES PROGRAM
Adult Day Center, 4500 Peachtree Rd., NE, Atlanta, GA 30319
(404) 262-7271

Emergency Clearance Form

Participant's Name ______________________ SS # ____-____-____

Address ______________________ Phone ______________

Zip Code ______________________ Birthday ______________

Caregiver's Name ______________________ Home Phone ______________

Address ______________ Zip ________ Work Phone ______________

Person to contact if Caregiver is unavailable:

Name ______________________ Home Phone ______________

Address ______________ Zip ________ Work Phone ______________

I want to make sure that there is no delay in obtaining medical and hospital care and treatment in the event of my unavailability. I authorize the official Alzheimer's Day Center staff to act for me in giving consent for medical treatment for

(name) ______________________

Primary Physician ______________________ Ofc. Phone ______________

Address ______________________ Zip Code ______________

Allergies ______________ Last Tetanus Toxoid ______________

Pertinent Medical History ______________________________

____

Current Medications ______________________________

I agree to assume responsibility for all expenses involved in receiving prompt medical care.

Date ______________ ______________________
Signature of Family/Guardian

12/85

11-65

Attachment P

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.
ATLANTA AREA CHAPTER COMMUNITY SERVICES PROGRAM
4500 Peachtree Rd. N.E., Atlanta, Ga. 30319

Initial Interview and Evaluation Form

Date____________________

Participant's Name______________________________ S.S.#______________

Address____________________________________ Birth date______________

______________________________ Zip_______ Phone____________________

Caregiver's Name__________________________ Home phone______________

Address____________________________________ Work phone______________

Place of employment____

Are there other family or friends who help as caregivers?_____________

Name______________________________________ Home phone______________

Address____________________________________ Work phone______________

____

Name______________________________________ Home phone______________

Address____________________________________ Work phone______________

____

Please describe your greatest need in the care of the applicant:

When did the applicant first develop symptoms of dementia?

Is there a diagnosis of Alzheimer's disease?

If yes, when was the diagnosis made?

Is there chronic or other illness?

Does the applicant use a

Walker? Cane? Glasses? Dentures?

How does the applicant manage with:

1) Bathing?

2) Dressing?

3) Toileting?

4) Mobility?

5) Eating?

Does this person: need a special diet?

have any food allergies?

How does the applicant manage with:

Telephoning?

Money management?

Cooking?

Driving?

What was the applicant's personality like before becoming ill?

Is there any noticeable mood disturbance?

Depression?

Suicide risk?

Aggressive behavior?

Verbal aggression?

Hallucinations?

Sundown syndrome?

Catastrophic reactions?

Can the applicant follow verbal instructions?

Does the applicant have the ability to recognize faces?

What was the applicant's previous employment?

What are the applicant's favorite activities?

Has the applicant ever been in a day center or senior center before?

If yes, for what period of time?

Does the family or applicant have contact with other community agencies?

Which days of the week would you use the program?

Monday Tuesday Wednesday Thursday Friday

Please specify the hours you prefer:________________________________

Do you as Caregiver, have health problems?

If yes, will you please describe?

Resources:

1040____________ Social Security_____________Disability_____________

Impression:

Attachment Q

8:00-10:00 Orientation - Paper - Coffee - Clean-up

10:00-10:30

10:30-11:00

11:00-11:30

11:30-12:00

12:00-12:30

12:30- 1:00

1:00- 2:00 Lunch

2:00- 2:30

2:30- 3:00

3:00- 3:30

3:30- 4:00

4:00- 4:30

4:30- 5:00 Social Time

VOLUNTEERS	COMMENTS

The Family Respite Center: Day Care for the Demented

June 1986

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This work has been performed for and submitted to OTA.

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PLANNING

The Alzheimer's Disease and Related Disorders Association, Northern Virginia Chapter (ADRDA-NOVA) is a local chapter of a national organization which was founded less than five years ago. The organizations' primary charge is to provide family support, community education and research assistance regarding conditions which result in dementia. Individual chapters also have the responsibility for aiding afflicted individuals and their families in their search for support services. ADRDA-NOVA has been in the forefront in identifying community needs and helping families take advantage of existing services. As gaps in services are identified , the chapter has been instrumental in creating solutions to these problems. In 1983 the chapter worked with a local hospital to establish the Dementia Resource Center, multifaceted health center for the demented. This provided a community focus for dementia, a diagnostic clinic and management; counseling and educational services for family members; and a speakers bureau for community education. Shortly after the development of the DRC another gap in community services was recognized; there was no adult day care for the severely impaired patient with dementia.

This paper will describe how a new service evolved from a good idea into a five day a week operation. This center, the Family Respite Center (FRC) is unique in Northern Virginia because its' client population is all are demented and because it maintains a role as a sister organization of ADRDA-NOVA.

A Chronological Review

The origin of the Family Respite Center can be traced back a meeting of an ADRDA-NOVA support group in 1982 wherein family members expressed their need for help in caring for affected relatives late in the stages of their disease. As these patient's diseases progressed and they became more demented, many were turned away from daycare centers that they had been attending or were refused admission to centers as new participants.

Although it took an enormous personal committment, family caregivers wanted to maintain their relatives at home, in their own community. For the majority, there was a positive desire to maintain the patient in a noninstitutionalized home-like environment for as long as possible. In addition, a significant number of families could not afford the twenty thousand dollars a year or more required for a nursing home. So at a time when the burden of care was increasing, help available in the community was decreasing. Family members would resist the recommendation of nursing home placement, but often had nowhere else to turn. Typically, the only alternative was to hire professional caregivers or sitters for the time when a family member was not available. The cost of this was significant and often these individuals were not available or were not available in a reliable fashion. They were untrained in care of the demented and frequently would not return after one or two visits.

The members of the ARDA NOVA Chapter brought this dilemma to the attention to the general membership and to the Board of Directors of the chapter. A variety of formal and informal discussions ensued. Families wanted a place that would give them a break from the relentless demands of caregiving particularly during the later more difficult stages of the disease. It was clear that there was a gap between the perceived needs of the family members and the existing care facilities in the community. In particular troublesome behaviors for daycare centers would include problems with incontinence, wandering or other behavioral problems. These "other" problems mentioned by family members included aggression directed towards staff or other participants in the center or interfering with the staff or other participants as well. Many Alzheimer's patients go through a period of increased motor activity which can be disruptive without actually interfering with other individuals activities. A number of patients simply did not participate in the activities of the Center and often the staff was frustrated by this and did not feel they were providing a useful service to these individuals.

The Chapter responded by forming a planning committee which addressed three initial considerations. First was to ascertain the resources currently available in the community. Second was to document a reasonably broad base of support for and anticipated participation in the center. Third was to identify a program of care which would remedy the difficulties experienced by the ARDA NOVA families. The Chapter was fortunate in receiving an initial promise of financial support from the Knights of Columbus, Mount Vernon Council. This support allowed the ADRDA-NOVA Chapter to investigate the situation and resulted in planning for an independent alternative daycare center.

During the summer of 1983 members of the ADRDA NOVA planning committee made site visits to a number of adult daycare centers and contacted others by phone. No existing adult daycare center in the geographic area met the requirements of the ARDA-NOVA community. However, two centers were identified which catered specifically to victims of Alzheimer's type illness. These programs were The Harbor Area Adult Daycare Center in Costa Mesa, California and the Burke Rehabilitation Center in White Plains, New York. Both of these centers had effectively addressed many of our issues. Mrs. Lin Noyes was able to make site visits which provided a concrete example that a number of ADRDA goals could be met in a reasonable fashion. The Harbor Area Adult Daycare Center visit had a significant impact on planning. (Sands, 1983) In addition to giving families respite it was clear that many of their clients responded to the program by improved performance, increased life satisfaction and a slowing of their functional decline. As a result of these site visits the goals of the proposed center Center were redefined to include a therapeutic effect on the participants in addition to relieving the burden of the family.

With all of this information in hand ARDA-NOVA hired a healthcare consultant to put together a proposal for what was to become the Family Respite Center. The planning committee felt that actually writing a formal plan for a venture such as this was beyond the scope of a volunteer group. The issues here were time, expertise, and experience; particularly if the project were to be done in a timely fashion. The consultant, relying heavily on the experiences at Harbour Area and Burke Rehabilitation Centers put together a practical plan on how to open and run the daycare center. This took six weeks. In November of 1983 the proposal was accepted by the ADRDA Board. The plan accompanies this report (Appendix A).

Finding space took six months. In June ,1984 the Archdiocese of Arlington made available an unused portion of a parochial high school for one year only. The disadvantages of having to move were weighed against the advantages of no rent and the space's immediate availability. It was decided to accept the Bishop's offer thinking it was better to "sell" a viable program rather than an idea. During the summer cleaning and renovation was performed with considerable help from community volunteers. In July, 1984 the Family Respite Center became a non-profit corporation and in September the doors were opened on a part-time basis (three days a week). Full-time functioning was reached in April 1985.

Once the initial operation had begun the issue of a permanent home had to be addressed. In January of 1985 the search for space began again. This resulted in an ongoing re-evaluation of potential need, possible locations, projections of expenses and revenues all of which had to be considered in the context of each possible site. Finally the Chesterbrook Presbyterian Church in Falls Church, Virginia was selected. This was close enough to the original location to honor the committment to the original clients and it was also closer to areas with large populations of elderly individuals. Rent at this site was low since the church is also non-profit, and this kept costs low as well. In June of 1985 the Center moved to its present quarters.

In summary the key elements for the successful planning of this Center were a clearly defined need; a committed parent organization; and a specific goal. Of particular importance in turning concern or interest into a concrete plan was the initial donation of $11,000 from the Knights of Columbus.

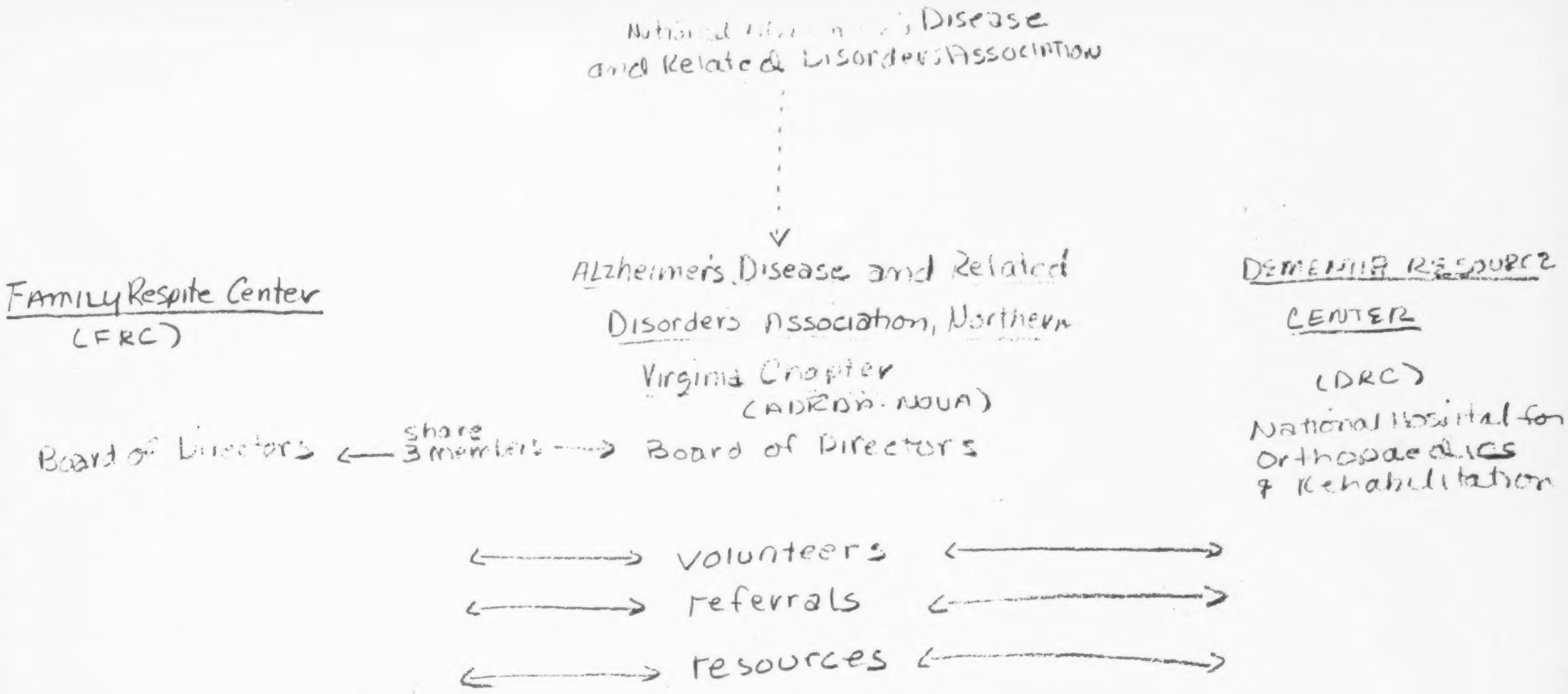
Funding

The gift from the Knights of Columbus was the initial source of money for the FRC. In the beginning the only other source was individual donations to ARDA-NOVA ear-marked for the center.In July 1984 the Knights of Columbus gave another $5000 for a total of $16000. This was the funding for the costs of planning the center and the initial start-up. The Clark Charitable Trust made a large donation of $50000 in December, 1984. This with a smaller grant from the Northern Virginia business communityguaranteed the centers solvency for a year of operation. This allowed the director and the Board of Directors to concentrate on issues of quality of care and evolving the program rather than searching for funds to keep the doors open. In addition the local business donations gave the center credibility and heightened local awareness of the Center's activities.

Administration & Operation :

1. Organizational Structure

The Family Respite Center is a not-for-profit 501(C)(3) corporation registered in the Commonwealth of Virginia. During the initial discussions a variety of structures were considered. A co-operative was an initial choice, but Virginia does not allow them to have tax exempt status. This was a great economic barrier. The lack of a professional staff was felt to be a significant liability both in terms of reliability and marketing. The time committment of working caregivers would also preclude their participating in such a structure. For these reasons, the Coop idea was abandoned. A for profit adult daycare center was felt to be inconsistent with the goals of the parent organization. It would have required significantly more capital to get started and there would not have been the cooperation of the other charitable institutions which have facilitated the Center. There was also the potential that the need to make money would compromise the committment to expand and innovate in the area of dementia daycare. The possibility of having the Center as a subsidiary of the ARDA NOVA Chapter was considered. This was rejected for a variety of reasons. Most concrete was the legal liability that ARDA would have to assume. ARDA-NOVA is a volunteer organization with a variety of obligations. Running a day care center would have stretched its' resources and would clearly be outside normal chapter duties and there was the potential conflict of interest for ARDA when it had to deal with other suppliers of adult daycare in the community. It would also divert many of the resources available to the ARDA Chapter from its role in the community to serving the relatively narrow focus of the Family Respite Center. Eventually an independent corporate structure for the FRC, was selected with its own Board of Directors. There are overlaps with the ADRDA-NOVA Board of Directors but The relationship between the two organizations is



National Alzheimer's Disease
and Related Disorders Association
FAMILY Respite Center
(FRC)
Board of Directors
share
3 members
Alzheimer's Disease and Related
Disorders Association, Northern
Virginia Chapter
(ADRDA-NOVA)
Board of Directors
DEMENTIA RESOURCE
CENTER
(DRC)
National Hospital for
Orthopaedics
& Rehabilitation
volunteers
referrals
resources

Figure 1. Relationship of ADRDA-NOVA, FRC and DRC

cooperative but distinct. This relationship of the Family Respite Center, ADRDA-NOVA and the DRC are shown in Figure 1.

As with any formal corporate structure there is a Board of Directors which oversees the corporation and a set of bylaws by which the corporation is run. The corporation must pay $25.00 annual fee to the state and report major changes in organization in a regular fashion.

The initial 501(C)3 status was granted provisionally after an initial evaluation and in 1989, the fiscal records of the corporation will be submitted to the IRS and reviewed. At that time a final determination will be made. This tax-exempt, non-profit status is very important in pursuing donations. It also generates a certain altruistic credibility about the center in the community. A lawyer was engaged to obtain the status and an outside accounting firm is employed to make sure financial records are in order.

Licensure

The Family Respite Center is licensed by the Dept. of Social Welfare of the Commonwealth of Virginia. This requires a zoning permit, a building inspection, a Health Department inspection and a fire inspection. It encompasses a global review of the Center's facilities and activities. There are strict requirements with respect to the number of clients and the amount of space and facilities that have to be provided. This resulted in only minor changes in our physical plan. The licensing of non-profit daycare centers in Virginia is not mandatory. The Board felt that obtaining licensure was a way of contributing to the establishment a community standard for adult daycare for the elderly. It also reinforced the idea that adult daycare centers should be monitored in order to maintain adequate standards of care for the participants.

Board Of Directors

The initial Board of Directors for the FRC were members of the ARDA-NOVA Planning Committee. The bylaws stipulate that three of the FRC Board members will alwyas be members of the ADRDA-NOVA Board of Directors. This was done to preserve the original character of the organization. The interlocking directorate facilitates the innovative and exploratory aspects of the ARDA-NOVA Chapter as it was reflected in the evolving concept of dementia specific adult daycare in this community. It assures that the people in the community would have access to the FRC at all levels including the decision making and planning level. It also guaranteed a number of members of the board who had a personal and individual committment to patients with Alzheimer's Disease. A selection of Board members were taken from outside the ARDA Chapter in order to maintain the independence of the two organizations and preserve their somewhat divergent purposes. Board members were recruited on an individual basis by personal contact. Much of this was done to facilitate a specific purpose such as financial planning, fund raising, or marketing. The Board was specifically designed to be a working Board. A provision was made for a second honorary Board which would include individuals who had an interest in the Center and were willing to support it but could not make the significant time committment of the full Board members.

Board meetings are required quarterly, however, extraordinary meetings have occurred on a monthly basis to meet the needs of the rapid evolution of the Center. There is provision in the by-laws for telephone polling of the Board which ensures an active involvement in major decisions. The Board of Directors sets policy for the Center's operation, approves a yearly budget and acts on applications for scholarship funds for individuals. The Board takes an active role in raising money for the Center in general and scholarships in particular. The Director of the Center is an ex-officio member of the Board and does much of the specific work on planning expenses. The Board has divided itself into smaller subcommittees to address specific tasks such as fund raising campaigns, planning renovations of the Center etc. These are generated and dissolved in an ad hoc fashion. All directors are volunteers. Expenses are reimbursed ,but no compensation is given.

Staff Of The Center

The center has a paid staff consisting of a director, assistant director, activity director, program assistants, and a general assistant.

Staffing.

The ratio of staff to clients is one to five and the is never decreased. Volunteers augment the staffs efforts. The involvement of volunteers is desirable because it increases the personal attention for each client and it brings a continuing fresh perspective to the center.

The Director Of The Center.

The initial responsibilities of the Director of the Center were two fold. First was the setting of a day to day policy and procedure for the initial start up period of the center. This was accompanied by a need to intergrate the Center with other services in the community including home health agencies and other short term respite resources. The Director has responsibility for an outreach program generating talks within the community. These talks raise the level of community interest in and understanding of Alzheimer's Disease. They also facilitate the community's appreciation for the role of dementia specific daycare in the clinical course of the Alzheimer's patient. The Director of the Center is responsible for the staffing of the Center, reviewing participant admissions and discharges, overseeing the functioning of the Center and acting as advocate during Board meetins.

Assistant Director. This individual is responsible for the day to day operation of the Center, orientation of staff, scheduling, and oversight of the volunteers program.

Activity Director And Program Assistants. The Activity Director is responsible for the activities of the clients on a by hour basis, helps plan activities for clients to create a balance of activity and rest. Two Program Assistants help the participants with their activities and personal care. Although these three have client contact as their principal responsibility, all staff members work with clients on a day to day basis. The Activity Director must have a degree, be able to lead groups and superivse the activities of the program assistants. There is a part-time General Assistant who functions as a "person Friday", helping with participants, Center operations or typing and office work. Specific job descriptions are shows in the Plan (Appendix A).

Staff Recruitment.

The position of Director of the Center was advertised widely in nursing and geriatric publications. The requirements were for an advanced gerontological degree, experience with demented patients and administrative skills. Once the Director had been selected that individual hired the staff. The rest of the staff was recruited locally through advertising in newspapers, bulletin board announcements and training sites. Several employees began as volunteers at the Center and subsequently decided to commit themselves to a fulltime working status. This required a provision for considerable on the job training.

The significant threat of continuity within the staff is their ability to manifest their general concern for the participants in the context of their dementing processes. They are able to perceive the participants as parts of a larger family and community structure who are helped by the FRC rather than as individual isolated clients who need custodial care. Certainly there is a considerable dedication and self sacrifice in these individuals. In addition to this strength of character there is a willingness to learn and adapt that is extraordinarily important. In part this is because the concept of dementia specific daycare is relatively new and still evolving. There is also such a diverse range of behavior that any individual client can manifest that the workers must be able to learn and respond to this variability.

ORIENTATION

The new staff is formally oriented by the Director and Assistant Director. This introduces them to the Center's policies, philosophies, activities and programs. There is in depth instruction in the nature of Alzheimer's Disease and other dementing conditions. Millieu therapy is explained and the employees' role in the participants environment is emphasized. There are specific instructions in individual caregiving techniques. In such a small operation informal orientation is as important as formal orientation. This is accomplished through a cooperative group effort. Senior staff is expected to orient new staff by providing a role model as well as instruction. When group weaknesses are identified staff meetings are used as an educational forum. Continuing education programs are held regularly ~~and~~ t update the staff on advances in the field. New staff and volunteers are encouraged to attend programs sponsored by the FRC or ARDA-NOVA to increase their knowledge and skills. A small amount of money is set aside by the Board of Directors for continuing education.

On the job training is extensive and new staff members are not left alone with the participants until the whole staff is comfortable with the situation. It is also important that the clients are also comfortable with the new staff and this is also taken into account.

Day to Day Operation

The Center is open five days a week Monday through Friday from 7:30 am to 5:30 p.m. The hours were chosen to accomodate the caregiver who commutes to work and staff hours are staggered to accomodate a 10 hour day. The Center has a schedule of planned activities for each day which are chosen to meet the clients needs for physical exercise, entertainment and facilitation of communication skills. The staff is expected to balance the need for structure during the day with the variable needs of the group on any individual day. Staff members are expected to be aware of the individual client's mood and day to day changes in lucidity. This is done to tailer activities to meet individual needs. Participants are never forced to join in activities. Every client is reinforced for their participation in an activity no matter how tangential that participation may be. Even individuals who choose not to join in an activity are asked how they perçeive or feel about the activity. In this context improving the client's self image concomitantly improves their community living skills. As they are intergrated into a group and function within in it, their physical and social adjustment improves. In many cases their personality returns toward their premorbid state.

Budgeting And Revenues

The FRC has a maximum capacity of twenty patients per day. The daily fee of $22.80 was calculated to allow the center to roughly break even at capacity. We were aware of the number of indigent elderly. No patient has been turned away from the center for lack of funds. The center does not anticipate covering expenses from client fees as we have an active scholarship program. Scholarships are partial or complete. Because of this program we will need continuing community support. The greatest source of revenue has been donations .Client fees have become increasingly important as the patient population has increased.

Most of the expenditures were directly related to program services. Salaries were the largest expense. During the first year a number of none-recurring expenses such as consulting fees, moving expenses and legal fees were incurred. Rent , food , insurance,and consumables were the primary expenses. A copy of the first annual report accompanies this paper and details the centers financial picture. (Appendix B)

PROGRAMMING

The original therapeutic goals for those who suffer with Alzheimer's Disease were very limited. In general they were vague, symptomatic and not found to be particularly helpful by families and professionals given the task of the day to day care for demented individuals. The knowledge that the disease itself is inherently progressive tempered much of the health care community's enthusiasm for working with these individuals. Practical plans for implementing the circumscribed goals which existed were virtually nonexistent.

Milieu Therapy

During the 1960's the Institute of Gerontology at the University of Michigan applied the theory of therapeutic milieu with a group of older adults, many of whom were suffering significant cognitive decline. (Boudreault, M.F., 1975) In a descriptive study they were able to identify certain elements in the environment of older, confused people which enhanced their ability to regain or maintain levels of function. They also were able to document an increase in participants satisfaction with their lives.

The planners of the FRC were first introduced to the concept of therapeutic milieu for Alzheimer's patients at the Harbor Area Adult Day Care Center in Costa Mesa, California during an on site visit before the FRC opened. This visit had a significant impact on our plans for the Respite Center. The original plans were somewhat limited; providing supervision for individuals that no one else would take in was the primary goal. The planing committee had decided to provide whatever services were necessary to give the families of the participant some respite during the work day. The emphasis was on the family and their needs, not on helping the individual participants or designing a program with therapeutic potential. In discussing the effectiveness of the day care center at Costa Mesa with their participants , families and staff, it became clear that there is a global improvement in the level of functioning of the clients and their families with the institution of milieu therapy.

The Michigan group had been able to document that a carefully constructed environment could produce significant improvement in the performance of patients with dementia. The Harbor Area Adult Daycare Center was a demonstration that this experiment could be translated into working model. In essence a structured, sheltered, supportive_^_is created. The patient becomes comfortable in an environment they are familiar with. This includes the staff of the Center, the physical plant and the other participants. The individual is encouraged to work in a

how freq is parent- [illegible]? Is it a provision for other partic [illegible] for the "newcomers" cooperative fashion with the staff and other participants. The tasks which are generated are in some sense functional and parallel the patterns of their prior life. The participant receives an appropriate amount of cheerful support and appreciation for their activities within the context of this environment. This produces a significant increase in life satisfaction which may not be remembered as a specific cognitive event but which seems to improve the overall emotional welfare of the participants.

This type of programming requires a staff who can innovate and yet maintain the integrity of a structured environment. Group leaders must be able to recognize when specific activities are not appropriate or not well received either by the group or an individual. They must be able to modify activities to meet both group and individual needs on any given day. Specific techniques used in programming this kind of flexibility include altering the duration of an exercise or activity and activity can be changed from an individual to a group activity. Alternatively, the group's response can be used to facilitate the care of an individual.

The overall thrust of this kind of a program is to encourage participation in as normal a fashion as possible. This will vary from individual to individual and from time to time.

The program goals of the FRC are stated as follows:

> to provide a day care program of stimulating, social physical, and creative activities for elderly persons with Alzheimer's disease and related disorders within

an accepting and supportive environment and which are aimed at minimizing the loss of physical functioning, social isolation and inactivity and maximizing the potential of each unique individual;

to provide respite care and support for the members of families caring for persons with Alzheimer's disease and related disorders; and

to provide an alternative to institutionalization which will allow persons with Alzheimer's diseases and related disorders to remain in their own homes for as long as possible.

Program Activities

Each patient has individual goals which are present during staff meetings. The clients present mental status, functional evaluation, past preference and personal needs are taken into account. A balance is struck between passive and active situations. These ob-jectives are then worked into the structure of the daily plan. A considerable effort goes into integrating all this into a plan for the group.

No one is ever forced to participate. As a result two or three activities at a time may be required to meet the groups needs.

The daily schedule will be as follows:

Plan for the Day

7:30-9:30 a.m.	Drop off for early arrivals; coffee and conversation
9:30-10:00	Arrivals by most participants; semi-

	structured activities, including current events discussion, group music, games, continual work on individual arts and crafts projects. Orientation to the day.
10:00-11:00	Armchair exercise
11:00-11:30	Snack break-Toilet
11:30-12:30	Varied Structured Activity Period, options including outdoor physical activity, guest speakers, slide or video presentation and discussion, Center maintenance, arts and crafts projects. Expressive therapy.
12:30-1:15	Lunch
1:15-1:30	Toilet
1:30-2:30	Video, slides, arts & crafts
2:30-3:30	Music, arts & crafts, exercise
3:30-4:00	Snack
4:00-5:30	Departures, structured individual activities,small group activities

Expressive Therapy

A unique component of the Center's program is expressive therapy. The Center's clients, by definition, have diminished memory and decreased cognitive skills. For many participants, particularly those with Alzheimer's Disease, language is particularly affected. Through art, music, and movement participants are given an opportunity to express themselves. Thoughts and feelings which have been walled in by increasing impairment are given an avenue of communication. By using

AMILY RESPITE CENTER, INC.
STATEMENT OF REVENUE, EXPENSES, AND FUND BALANCES-CASH BASIS
FROM JULY 13, 1985 (DATE OF INCEPTION) TO JUNE 30, 1985

REVENUE	
Donations	
Grants and Large Donations	$ 64,900
Scholarship Donations	5,025
Memorial Donations	598
Property Donations	4,800
General Donations	5,892
TOTAL DONATIONS	81,215
Other Revenue	
Client Fees	14,107
Fundraising -Net of Expenses of $ 572	1,597
Other Income	604
TOTAL OTHER REVENUE	16,308
TOTAL REVENUE	97,523
EXPENSES	
Program Services	
Consummables	1,535
Consulting fees	5,749
Depreciation	26
Food	1,097
Inservices	82
Insurance	1,654
Moving Expenses	2,032
Rent	2,850
Printing, Postage and Publicity	669
Salaries	12,133
Start-up expenses	981
Taxes-Payroll	646
Telephone	643
TOTAL PROGRAM SERVICES EXPENSE	30,097
Supporting Services	
General Administration	
Legal and Accounting	1,810
Office Expense	793
Salaries	7,508
Start-Up Expenses	245
Taxes-Payroll	400
TOTAL GENERAL ADMINISTRATION EXPENSES	10,756
Fundraising	3,169
TOTAL SUPPORTING SERVICES EXPENSES	13,925
TOTAL EXPENSES	44,022
EXCESS OF REVENUE OVER EXPENSES	53,501
BEGINNING FUND BALANCES	0
ENDING FUND BALANCES	$ 53,501

alternative cognitive input the isolation of these individuals is lessened. The art works produced are a way of monitoring the progress of the client during their stay in the Center. There is also a certain level of satisfaction and pleasure in the clients as they construct something individually or contribute to the work of the group. Currently full group art therapy sessions are held four times a week. If funding becomes available individual sessions are scheduled to begin this Spring.

EVALUATION:

The Family Respite Center has served participants for sixteen months and it has successfully achieved its primary goal of providing respite to the families of demented adults late in the stages of their disease. We have successfully managed those with a history of wandering and aggression and we have developed strategies to deal with incontinence. More importantly, by applying the theory of Milieu Therapy we have been able to program activities for the severely demented, provide education and support for their families and help our participants remain in their home and their community.

Our first Annual Report is included in the Appendix (Appendix B) and shows our progress during the first year. Summarily, it shows that we attained our program goals but have not yet reached our business goal of serving twenty clients per day, five days a week.

From a business point of view, the first year of the Center cost $53,501.48. This was well within the budget ($68,000) but only reflects 10 months of business and less than full enrollment. (See Fig.2) This translates into an average cost per day of $61.43. The cost was for an average of 5.38 clients per day. These figures are well above the ultimate cost of 22.80 per day but reflect start up and slow growth. By June, (the end of our first fiscal year), the average attendance was up 8.1 participant per day and by October this figure had reached 12.8 per day. By December, the cost of operating to $35 a day. Based on the first years' actual expenses, the projections for next year show that 22,80 is still an achievable goal for 20 participants per day. However, this figure does not reflect accepting indigent participants and scholarship funds will still have to be raised to continue caring for those who cannot pay for their care. By December of 1985 we noted that we had lost 50% of our population due to death. In part, this was just a manifestation of some well known statistics from the state of California 25 years ago. There is a 50% one to two year mortality in patients who were institutionalized for dementia at that time. Since our facility was, to a large extent an alternative to institutionalization, it was quite clear that this was not unexpected and that we were in fact fulfilling our commitment to provide an alternative to nursing home placement.

Whether or not this Center can succeed from a business point of view remains to be seen and hinges on reaching capacity. Several issues surround the Center's ability to achieve a "full hours" status:

1. Community Awareness Of Program

Adult Day Care is a relatively new concept itself and is gaining acceptance as an alternative to nursing home care slowly.

Dementia specific day care is even newer and comes when society at large is just becoming familiar with dementias as illnesses, much less beginning to consider ways to help those individuals afflicted with severe memory loss.

2. Individual's Perceptions Of The Center

Families who utilize the Center at this point are very knowledgable about Alzheimers type illnesses, aware of their options for care and understand that the program has a therapeutic effect for their loved one. Caregivers who bring their relatives here are also most eager to avoid nursing home placement and are dedicated to caring for their relative in the community.

3. Referral Resources

Beside general community acceptance, acceptance of this type of Center by health professionals, and psycho-social community professionals is a slow process. Learning which demented people to refer and reassuring families about our services is slow in coming. Viewing our Center as "filling in the gap" between established day care centers and institutions has not been an easy concept to convey.

Lack of Additional Services

The Center has traditionally offered "no frills" services in an attempt to reach a cost effective status where Center costs are covered by Center revenue. There is no transportation or other services which are offered by other Centers above and beyond basic day care. The specialty is programming for the demented and being able to meet their needs in a therapeutic way. Because of our "shoe string" budget we cannot compete with the glitz of other centers. Although participants are generally not affected by these extras, families may perceive them as desirable for their loved ones. Clients who may be more appropriately served in our Center go to others because the family is attracted by services beyond the basics. Whether or not this Center presents a viable alternative as an independent service, replicable by others remains a question. What can be answered at this time is the effectiveness of this type of service for the severelydemented. these individuals can be cared for outside of a nursing home at a cost less than nursing home placement would cost. Groups of severely demented individuals can function at a good level and individuals in late stages can achieve satisfaction from being part of a therapeutic milieu. The Center's presence in the community has had an effect greater than the provision of daycare for its own participants. It has become an educational site for professionals, educators, researchers and families to observe and learn techniques and philosophic guidelines for caregiving. It seems also to have had an effect on other adult day care centers who are now accepting incontinent participants. One area program has seen merit in special programming for the demented and now has special tracts within its center. One tract is the more cognitively impaired. Area nursing homes have approached the Center looking for guidance in starting special Alzheimer's units. Many in these groups are beginning to think about the special needs of the cognitively impaired and how best to meet those needs in a therapeutic way.

Objective testing to demonstrate improvements or lack of decline in function, participation in ADLS and life satisfaction care needed for evaluation of this Center. If the concept of independent center is not viable, what features in its programming can be extracted and applied in other settings? How to grow and build on existing knowledge of milieu therapy is an important question.

PLAN
FOR THE IMPLEMENTATION
OF AN
ADULT RESPITE DAY CARE CENTER

Sponsored by
Alzheimer's Disease and Related Disorders Association
Northern Virginia Chapter

Prepared under contract with
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I. BACKGROUND

Nancy L. Mace and Peter V. Rabins co-authored the book, The 36-Hour Day in 1981. It provides a guide for families of persons with Alzheimer's disease. The following sections draw extensively on their work.[1]

A. Alzheimer's Disease

While 85 percent of all older adults live out their lives with their mental abilities intact, the remaining 15 percent suffer from progressive memory loss, intellectual impairment, and the inability to care for themselves.[2] These symptoms comprise the clinical picture of dementia.

There are many causes of dementia, some of which, like thyroid disease, can be treated or cured. However, most dementias are progressive and irreversible. Alzheimer's disease, named after the German physician who first described the condition in 1907, accounts for 50 percent of irreversible dementia and is the fourth leading cause of death in older adults.[3]

The symptoms of Alzheimer's disease usually are a gradual, and sometimes imperceptible, decline in many areas of intellectual abilities and an accompanying physical decline. This neurologic disease destroys brain cells in an otherwise healthy person, and it is unknown as to what causes the disease or who is at risk for getting it.

Early in the illness only memory may be noticeably impaired. Personality may change or depression may appear. Later, impairment in both language and motor abilities are seen. At first, the person may be unable to find the right word or the wrong word may be used. Gradually, he/she will be unable to express him/herself and will be unable to make sense of the environment. An inability to understand explanations may occur, and previously easy tasks will become difficult. Eventually, Alzheimer's victims lose their ability to care for themselves, and need help with eating, dressing and walking.

Behavior problems often accompany the loss of intellect. Some victims wander and get lost, some become hostile and abusive and have uncharacteristic outbursts of anger, and others talk and babble incessantly. Late in the illness, they become incontinent and need constant supervision.

The course of the disease is variable. While some victims live only a year or two after diagnosis, others live ten years or longer.

There is no known cure for Alzheimer's disease, although research has increased in recent years. Researchers have found that the brain cells of Alzheimer's victims may harbor abnormally large numbers of senile plaques or neurofibrillary tangles, or there may be a loss of nerve cells. Diagnoses are made on the basis of the types of symptoms, the way the symptoms progress over time, the absence of any other cause for the condition, and a compatible CAT scan. However, a final diagnosis can only be made after a brain biopsy.

The magnitude of the problem of Alzheimer's disease and other dementias cannot be overlooked. Society is "growing older" and people who suffer from dementias are living longer with these diseases. Currently, over half of all nursing home beds are occupied by dementia victims, and Dr. David Drachman projects that one out of every three adults whose parents survive past the age of 65 will be involved in their care because of dementia.[4]

The disease destroys its victims little by little, and causes enormous emotional and financial problems for families and society. While researchers are vigorously looking for the causes and cures for this silent epidemic, we are faced with real problems in providing care and help in day-to-day living for over 1.5 million Americans.

B. Living with a Person with Alzheimer's Disease

Living with a beloved family member who has an incurable, deteriorating, chronic dementia places a heavy burden on the rest of the family. This is not to say that love, caring, joys, and pleasures cannot, and do not, remain. Many people discover a sense of pride in learning to cope with difficult situations. Many families rediscover one another as they work together in caring for the ill member. However, for our purposes we will focus only on the changes required and the stresses incurred by family members as they learn to readjust their lives to meet the needs of their loved one.

A wide variety of new feelings can be expected to be experienced by all members as they undertake to care for an Alzheimer's victim. Sadness, anger, helplessness, guilt, discouragement, loneliness, depression, grief, and exhaustion are all common and understandable.

Roles, responsibilities, and expectations within the family unit change when one member becomes ill with dementia. Often for the first time, wives must learn to maintain family finances, husbands must learn to accept household maintenance chores. Children are asked to grow up quickly and accept new responsibilities. The members of the family may need a new leader or "head of the household."

In adjusting to these new roles/responsibilities and the new feelings encountered, family members themselves often change. A spouse often can feel increased pressure at not having someone with whom to share family responsibilities. Children may find the role-reversal caused by the need to care for a parent a difficult adjustment. The knowledge that love relationships will never be the same will be difficult to accept. Outside interests are curtailed and time for hobbies or other recreational endeavors is lost. A philosophy of life and what's really important also changes.

C. Family Caregiving

Yet, in spite of all the stresses placed on family members, almost all families accept the responsibility to care for their ill loved one for as long as possible. The commonly held belief that families "dump" their sick elderly members into nursing homes or other institutions is just not true. While over $20 billion are spent on long-term care by public authorities and approximately $10 billion a year by private individuals, the greatest expenditures are borne by families who take care of frail members at home for as long as possible (a cost difficult to pinpoint but estimated at $38.2 billion a year by the U.S. Comptroller General).[5]

Interestingly, the National Council on Social Welfare suggests that "more people are placed into nursing homes because family resources and funds are exhausted than due to a change and deterioration of health."[6]

They go on to attest that "about three-fourths of all impaired adults are helped by their families, and not by a formal program. Some studies show that the elderly use their family, friends and neighbors five times as often as an organized service or agency."[7]

For every person now in a long-term care institution, there are at least two people with similar disabilities back home, most of them cared for predominately by family members. Between 60 and 85 percent of the care received by the impaired elderly is provided by relatives and friends who are not compensated for their time.[8] According to a 1978 HEW Task Force, between 3.6 and 7.8 million persons received long-term care services from families and friends, one-third of them needing constant, rather than partial or intermittent, care.[9]

Perhaps it is the strain caused by the need for constant supervision that causes the most stress on family members. Families report that their greatest problems are in coping with the mental conditions of their loved ones, as opposed to their physical impairments.[10] Those people who have had the actual experience of providing long-term care to a family member do not say that it is financial assistance that is their primary need, but rather it is community support services, including help for their disabled loved one and relief for those that are providing the constant care.[11]

D. Respite Day Care

When examining the support needs and interests of family caregivers of persons with Alzheimer's disease and related disorders, several concerns become apparent: 1) To obtain a support service which will provide the best quality assistance to their ill loved one; 2) To allow their loved one to remain in their own home for as long as possible, rather than prematurely moving into an institutional setting before skilled nursing care is required; and 3) To provide respite and support for the family caregivers in order to allow the time necessary to conduct personal business and social affairs, as well as to recoup the energies required for supporting their ill family member. An adult respite day care center provides for all these needs and interests.

Day care is a unique service because it can meet the long-term needs of those seeking service while also taking into account individual differences. It differs from outpatient services and senior centers in several important aspects: services are tailored specifically for each participant; each service has a therapeutic objective; each day is planned for each individual; and activities are not chosen at random by the participant.[12]

Surveys of elderly people have found that the great majority prefer to remain in their own homes for as long as possible rather than enter other residential institutions. Robert Butler, former head of the National Institute on Aging, describes the response as coming from an understanding that "home is extraordinarily significant to many older persons. It is their identity, a place where things are familiar and relatively unchanging."[13] This tenacity to remain at home is probably associated with a fear of loss of dignity and independence, contact with loved ones, and a fear of dying. And although loved ones share this interest, some, lacking the support required within the community, prematurely place their ill member in an institutional facility before skilled nursing care is required. The National Conference on Social Welfare (NCSW) reports that "as much as 20% to 40% of the nursing home population would be cared for at less intensive levels if adequate community-based care was available."[14] The American Association of Retired Persons suggests that "the goal should be to get the institutionalized elderly to lower and more appropriate levels of care where possible."[15] They go on to say that "publicly and privately supported patients in nursing homes who would be able to reside in their communities if proper support services were available and accessible ought to be assisted in doing so."[16] Further, they note that "the family currently receives little assistance in caring for dependent elderly persons in their own homes."[17] And the NCSW concludes that "adult day care centers offer the disabled person the opportunity to continue living at home while providing supervision during the day, and at savings . . . over the cost of nursing home care."[18]

A recent study of 450 day care centers that serve persons with Alzheimer's disease and related disorders revealed that the majority served at least a "few" demented adults, and that 5 percent of the centers served primarily the "seriously" demented adult. For this latter group, the programs were able to provide service successfully up to only weeks before death. In on-site visits to these facilities, the researcher found that the social opportunities provided to the clients were "good for them," "allowed them to make friends," and gave them a chance "to benefit from social interaction."[19]

Relief through a day care program for family members providing full time care and support to a loved one with Alzheimer's disease not only can provide the ill person with a positive experience, but also will do much to allow that person to remain in their own home for a longer period of time (therefore, also providing for a cost-effective alternative to institutional care). The provision of 1-3 days per week of day care can allow the family caregiver time to take care of business or maintain some social activities outside the home, and do much to provide a period of rest from the constant demand for support. And for the family, this time apart can make the time together more pleasant.

II. THE NEEDS FOR ADULT RESPITE DAY CARE FOR PERSONS WITH ALZHEIMER'S DISEASE IN NORTHERN VIRGINIA

A. Number of Elderly in Area

As reported by the Northern Virginia Planning District, there are approximately 56,000 adults over 65 years of age currently residing in the Northern Virginia area. These consist of the following:

- Fairfax County: 28,000
- Arlington: 18,000
- Alexandria: 10,000

Total 56,000

B. Number of Persons with Alzheimer's Disease and Related Disorders in Area

The National Institutes of Health in their 1981 publication, "The Dementias--Hope Through Research," reports that "5% of the U.S. population 65 or older is severly demented. Another 10% may be mildly to moderately impaired."[20] It is from this group that our program will draw its clients. If we consider these figures for the Northern Virginia over 65 population, we note that 8,400 persons are eligible for the proposed audlt respite day care center. This breaks down as follows:

- Fairfax County: 4,200
- Arlington: 2,700
- Alexandria: 1,500

Total 8,400

C. Currently Operating Adult Day Care Programs in Area

Northern Virginia has four operating adult day care centers. Below are cited the client capacities and current enrollment.

	Capacity Per Day	Current Enrollment
Annandale Center (Fairfax)	30	35
Madison Center (Arlington)	35	60
Woodbine Convelescent Center (Alexandria)	20	19
Leewood	50	30
Total	135	144

These facilities all provide service to a few persons with Alzheimer's disease. If we can assume that the existing programs serve 10 percent of the mild to moderately impaired in combination, perhaps 14-15 persons with Alzheimer's disease are currently receiving care. However, as the disease progresses and behaviors such as wandering, agitation, and incontinence become more pronounced, these facilities cannot adequately provide proper care.

It is clear that the currently operating day care programs, while beginning to address the need are set up to serve the mentally intact and, therefore, do not have the capacity to serve those who exhibit the behaviors associated with the later stages of Alzheimer's disease and related disorders. Further, as reported by Sands,[21] and reiterated by Mace,[22] homogeneity of the participants is a key factor in the success of day care programs for persons with Alzheimer's disease and related disorders.

D. Unmet Need in Area

Many of the people in need are known to the Alzheimer's Disease and Related Disorders Association (ADRDA) Northern Virginia Chapter. The availability of such a new support program can easily be made known to them through the Association's mailing list. In addition, referrals from the four currently operating centers would be welcomed.

In responding to the requests of several of its members to explore the feasibility of creating such a program, ADRDA/NOVA distributed a questionnaire at its September 1983 monthly meeting (See Appendix A.) Twenty-two responses were submitted from those in attendance. The results are as follows:

- 13 of the 22 respondents said they currently needed and would use such a facility if it were available.
- 8 respondents requested care 4-6 days a week; 4 specified their interest in care for 1-3 days a week.
- 10 respondents requested full-day service; 3 others wanted half-day care.
- Respondents suggested a willingness to pay between $3-4/hour for the receipt of such care.
- 15 offered to provide some form of volunteer services to defray the cost of care.
- Only 2 respondents requested assistance with transportation, whereas 10 others said they could manage their own.
- And, 15 of the respondents expressed an interest in participating in the planning of the new program.

E. Advice from Others

With these needs in mind, the ADRDA chapter sought the advice of other groups throughout the country who have had similar experiences in creating and providing day care services for persons with Alzheimer's disease and related disorders. Visits were made to the Burke Rehabilitation Center in White Plains, New York, the Judson Park Day Care Center in Cleveland, and the Harbor Area Adult Day Care Center in Costa Mesa, California, where the President and a member of the Respite Day Care Committee attended a three-day workshop in creating a day care program for persons with Alzheimer's disease and related disorders.

F. Conclusion

Based upon our assessment of the current need for adult respite day care for persons with Alzheimer's disease and related disorders and their families in Northern Virginia, as well as the advice obtained from others who have had similar experiences, we have determined that an initial client load of 3-5 per week, growing to 20-25 persons by the end of the sixth month is most realistic. The program to be provided for these persons in need is described below.

III. THE PROGRAM

Proposed below is the creation of an Adult Respite Day Care Center for families of persons with Alzheimer's disease and related disorders living in Northern Virginia. Many of the ideas used to formulate this section were obtained from the Harbor Area Adult Day Care Center (Costa Mesa, California), Dan Sands, Ph.D., Director.[23]

A. Program Philosophy

The essential philosophic assumption upon which the day care center is based is that the total environment of the program is itself a major factor which needs to be developed and used in a manner to provide a climate of positive support for all those operating within it. This philosophy, used as the basis of the successfully operating Harbor Area Center, recognizes that each of the environmental components--the activities, the physical setting, the staff, and the participants themselves--have the potential for providing a positive (or negative) impact on the success of the program.

One's social and physical environments have a profound influence on behavior, attitude, and self-image. Coons describes this theory as "milieu therapy."[24] The expectations of those around us, the limits placed on us by our physical setting, the rules which govern us, and the activities in which we engage (or don't engage) determine much of our behavior, how we view ourselves and our world. Living in a barren setting lacking in challenging activities and social interactions produces a defeatest attitude, isolation, and a poor image of ourselves. Conversely, an environment rich enough to provide a range of activities and a variety of positive social experiences, allows us to maximize our potential. We expect to create such an environment, one which provides this opportunity through challenging activities, positive social experiences, and a comforting physical setting.

Our philosophy recognizes that program participants will benefit most when:

- The program environment offers opportunities and experiences which allow participants to maximize their potential;

- The program is designed to provide a broad range of structured, and individualized, experiences which place positive, realistic expectations on all participants; and
- The program provides a homogeneous grouping of individuals, which allow each person to achieve their own potential level of independence in accordance with their own unique set of needs.

The philosophy leads us further to the following understanding of the rights of program participants:

- No participant shall be denied service due to gender, race, creed, or economic status.
- The program shall provide adequate and varied activities which maximize potential and encourage self-care.
- Participants and their families will be closely involved in developing their program activity schedule.
- The program will be provided in a clean, sanitary environment which is safe and in good repair.
- Participant records shall be considered confidential and shall only be open to staff on a need-to-know basis. Information about participants shall not be released without written approval.
- Particpants have the right to voice grievances without reprisals.

The implementation of this philosophy within the program itself is the challenge we have set before us.

B. Program Goals

Based upon our program philosophy, we have developed a set of program goals. These broad statements of intent are designed to provide an overall long-range perspective to guide and focus the program's direction. Our goals are stated as follows:

- To provide a day care program of stimulating, social, physical, and creative activities to elderly persons with Alzheimer's disease and related disorders within an accepting and supportive environment and which are aimed at minimizing the loss of physical functioning, social isolation and inactivity and maximizing the potential of each unique individual;
- To provide respite care and support for the members of families caring for persons with Alzheimer's disease and related disorders; and
- To provide an alternative to institutionalization which will allow persons with Alzheimer's disease and related disorders to remain in their own homes for as long as possible.

C. Admissions

1. Policy

Any person with Alzheimer's disease or related disorder residing in the Northern Virginia area will be eligible to participate in the Adult Respite Day Care Program if he/she meets the following criteria:

- The type of support and supervision required can be provided by the Center;
- The participant is compatible with the other program participants; and
- The needs of the participant can be met by the program within the limitations and restrictions of the program's license to operate.

2. Procedures

The following procedural steps will be taken to admit a new program participant.

a. A review of the initial referral will be made, and if it is not from the participant's physician, an Approval for Participation form will be requested. (See Appendix B.)

b. An appointment with the potential participant and family caregiver will be scheduled for an initial interview and screening. At this time the program will be explained, fees discussed, and, if the participant and family are interested, a Release of Information and Initial Referral Sheet (Appendix C) will be completed. In addition, a Client Record Data Base form (Appendix D) will be set up, and Emergency Procedure form (Appendix E) completed, and the Patient Interest Profile (Appendix F) and Activities of Daily Living form (Appendix G) sent home for completion prior to entry into the program.

c. When all of the entry forms are completed, the staff will meet to review the materials and ascertain whether the program can provide the support required, and whether the potential participant will fit appropriately into the program.

d. An affirmative decision to admit a new participant will lead the Center Director to assign staff based upon the participant's needs. The staff will observe the new participant while in the program for two weeks to become more familiar with his/her needs and interests.

e. After two weeks of observation, an Individualized Program Plan will be developed based on the initial assessment interview, materials reviewed, and observation. The Plan will contain measurable program objectives in each of the following areas:

- Communication;
- Physical and medical;
- Social;
- Program Activities;
- Ambulation; and
- Self-care.

A specific program and schedule will be built around the Individualized Program Plan objectives which, in combination, will be designed to maximize the potential of the participants. This step completes the admission process.

D. Program Activities

Individualized Program Plan objectives will be achieved through participation in a stable, structured program built around a daily schedule of activities which also will allow for necessary individual variations and choices. The program will be designed to meet the participants basic human needs, including:

- The need for recognition;
- Maintenance of self-esteem;
- The development of meaningful relationships;
- Activities which are structured, yet varied enough to provide for individual choices; and
- Personal space.

Recognition will be facilitated by encouraging clients to participate actively in the program and then enthusiastically acknowledging their accomplishments. Staff efforts to maximize independence will be provided through participant involvement in various activities (e.g., preparing snacks, setting tables) which enhance self-esteem. Small group activities will provide the opportunity for cohesiveness, developing relationships and encouraging mutual help. The expected variability in ability/

disability among participants should allow almost everyone to be at least occasionally of help to someone else. The flexibility of activities should allow each participant to exercise choices and control over his/her own environment.

The daily schedule will be as follows:

Plan for the Day

7:30- 9:00a.m.	Drop off for early arrivals; coffee and conversation
9:00-10:00	Arrivals by most participants; semi-structured activities, including current events discussion, group music, games, continual work on individual arts and crafts projects. Orientation to the day.
10:00-10:30	Armchair exercise
10:30-11:00	Snack break - Toilet
11:00-12:30	Varied Structured Activity Period, options including physical therapy, occupational therapy, speech and communication, craft projects, discussion group on topic of mutual interest, counseling, gardening, table games, food preparation, music and dance.
12:30- 1:30p.m.	Lunch
1:30- 3:00	Varied Structured Activity Period, options including outdoor physical activity, guest speakers, slide or video presentation and discussion, Center maintenance, arts and crafts projects.
3:00- 3:30	Snack break - Toilet
3:30- 4:30	Special therapies--art, dance, music, drama
4:30- 5:00	Support groups/discussion
5:00- 5:15	Wrap up
5:15- 5:45	Departure; some structured individual activities, TV, nap until pick up

Each of these periods is discussed below.

Drop off/Arrival

Strict adherence to a designated arrival time, whether early (7:30-9:00) or regular (9:00) will be necessary because a participant's adaptation to the program often will be contingent on becoming a regular group member. Participants will be scheduled, and expected to attend on regular days of the week. Attendance will be taken at 9:30 and if someone is absent, the participant's home will be called. (Obviously, family members will be advised to call in advance when an absence is expected.)

A staff member will be designated to greet all participants upon arrival. This will be an excellent time for gathering and transmitting information. This time may also allow for learning about changes in medications, personnel at home, concerns and illnesses. A few words at this time may reveal a problem, or a triumph, at home that may affect the patient's attitude or mood, or be used as an encouragement in the program.

Coats and hats will be hung in a separate area and out of sight of the participants to avoid requests for going home.

During this initial time period, participants will be reminded of why they are at the Center and what is planned for the day. This orientation exercise will be the foundation for the day and never will be omitted. Each staff person and participant will be reintroduced each morning. Name tags and photographs will be used. A brief factual point about each person will be included in the introductions (e.g., where from, name of article of clothing) to help identify the person.

A large portable chalkboard with date, day, month, year, name and address of the Center written in large letters will be prominently displayed to assist participation in orienting to time and place. Discussion of the season, weather, holidays, etc. will also be included.

Next, the daily schedule of activities will be discussed. It will also be written on a blackboard for all to see.

Perception activities to stimulate all the senses also will be included during the initial daily session. These may include art, music, horticulture, cooking, games, poetry, sports, and story telling. This period also will be useful for observing a participant's decline. Increased apraxia, loss of context, disorientation to person, place or time may be evident and require a change in the Individualized Program Plan.

- Exercise

Exercise and movement have positive effects on muscle tone, maintain range of motion, and help maintain alertness. It stimulates memory. Rhythmic clapping and stamping are good warm-ups. With a staff person demonstrating, participants will be asked to move their heads, necks, arms, and fingers. Appendix H offers a list of exercises. Props such as balls, dowels, or musical chimes will be used.

- Snacks/Lunch - Toileting

Snacks and lunch will not be used merely as a break in the program, but rather as an opportunity to provide nourishment, observe capacities for using table utensils, encourage good manners, and stimulate conversation. A staff person will be assigned to eat with each table of participants to encourage conversation and interrupt potential crisis.

Individual meals will be prepared off-site and brought in fresh each day. Dietary restrictions will be followed.

Snacks/lunch will be followed by a brief (15-minute) rest period to allow for clearing tables and toileting participants. These will be the only unstructured times for participants during the day.

A word on toileting and incontinence. Some participants will need no reminders to go to the bathroom, some will need verbal clues, while others will require full assistance. Families will be asked to provide changes of clothing or incontinence devices as required. Toilet needs will be maintained on a written schedule and posted inconspicuously for the use of all staff. Quiet reminders, where necessary, will be made. All staff will be expected to assist in this activity. "Incontinence in persons with dementia is usually not the result of a neurological disease which has made the person unaware of bowel and bladder control. Some of these behaviors can be modified."[25] Why a person is incontinent must be investigated. Sometimes it is due to disorientation--the person can't find the bathroom or is not able to communicate his/her needs. For others, incontinence is a means of expressing anger. A regular toilet schedule does much to manage a person who has become unaware or unable to control his/her bladder and bowel functions. Also, it is possible to retrain many people. Both of these techniques will be used to minimize the embarrassment felt even by those with severe intellectual loss. However, whenever participants become soiled, they will be cleaned.

- Varied Structured Activity (2 Periods)/Special Therapies

The two structured activity periods, as well as the special therapies session, will be provided in a manner designed to obtain a balance between too much and too little structure. Confusion and dependence are the two extremes. The idea is to provide enough structure to reduce confusion, and, at the same time, encourage independence.

Balance is the key to the use of activities, as well.

On the one hand, participation in an activity can be seen as making demands or expectations that can create feelings of pressure; on the other hand, not enough participation in activities can result in boredom or loss of interest. Activity is not to be used as an end in and of itself, but rather as a therapeutic tool.
The process is more important than the product.
Activities, and participation, will be designed to meet individual needs. For some participants, coming to the Center itself might be enough; for others, special challenges will be important. Appendix I provides some guidance on "Planning an Activity." Appendix J offers "Guidelines for Teaching Older Adults," both of which were developed by the Costa Mesa Center.

Several other relevant guidance materials for conducting varied activities also have been developed by the Harbor Area Day Care Center. These are found as "Craft Instructions," Appendix K; "Facilitating Techniques," Appendix L; "Feedback," Appendix M; and "How to Talk with Participants about Sensitive Subjects," Appendix N.

Depending upon the needs of the participants, consideration will be given to the use of homogeneous groupings. If, for example, participants exhibit a wide range of word-finding difficulties and language deficits, three groups (one stressing non-verbal activity, one for the disoriented/confused but possessing some verbal skills, and a third group for those with only minor cognitive impairments) will be created. If only minor variations are found, groupings may not be appropriate.

The use of art, dance, music, and drama will provide a wide range of opportunities for non-verbal as well as verbal expression. As therapy, they all have proven to be very successful. All will be used within the period devoted to these activities.

- Support Group/Discussion

Persons with Alzheimer's disease and related disorders are usually eager to discuss their disabilities in a group. Led by a competently trained and experienced professional, such support groups can prove to be very useful. A number of topics can be expected to be discussed. These may include group dynamics, the behavior of an individual in the group, and personal problems. The unique problem of Alzheimer's disease can be expected to be a central topic.

The sessions will be held in small groups around a table. Experience indicates that participants can be expected to discuss themes such as:1) the cause of these new difficulties; 2) loss--of ability to drive, friends, and level of independence; 3) the difficulty in word-finding; and 4) role reversal due to the growing level of dependency.

The staff-participant relationship will be used to facilitate discussion. Helping to identify the problem, clarifying the staff role as a helper, evaluating the nature of the concern (crisis or chronic), and mobilizing resources (family, friends, agencies) will be the process used by the group leader.

- Wrap-up/Departure

At the end of the day, the day's activities will be summarized for the whole group. The activity schedule on the bulletin board will be used for orientation. Participants will be reminded they are going home and who will be picking them up. Relaxing individual activities will be avilable while they wait for their pick up. The departure time will also be used to exchange information with family members, as well as share with them how the participant did during the course of the day.

E. Record Keeping and the Tracking of Participant Progress

Some records are necessary and useful in managing the day care program. In addition to those forms cited in the Admissions section above, the following informational materials will also be collected.

- The name and attendance record of each participant;
- A list of the participant's immediate family members and personal physician, with phone numbers;
- A personal statement by the caregiver of the participant's problems and symptoms;
- A list of each participant's current medications, including those which may be given during the day. (A designated place in the Center will be used to note the name, dosage, and time for receiving medications given at the Center); and
- A list of relatives in the form of a family tree to help identify obscure references in a participant's conversation.

The tracking of participant progress will be formulated around the Individualized Program Plan referred to above. In addition to the data obtained at admission (described in Admissions section), other baseline information will be obtained through the use of a standardized rating scale which measures the degree of disfunction due to intellectual loss on program participants and their families. Examples of these, provided by the Harbor Area Center, include the "Behavior Rating Scale," (Appendix O) and the "Burden Interview" (Appendix P). Observation of the participant's behavior during the first two weeks also will be critical. Appendix Q suggests a means of recording the results of the observations.

After completing the initial assessment, staff will develop measurable objectives around key goal areas. The following

"List of Treatment Goals," provided by the Long Beach, California Senior Day Treatment Center is exemplary.

List of Treatment Goals

I. Physical/Functional

1. maintain/improve health status
2. improve diet
3. improve self-care
4. increase ADL skills
5. increase independence

II. Cognitive

1. increase sensory stimulation
2. improve reality testing
3. increase utilization of cognitive functions
4. increase intellectual/cognitive stimulation

III. Emotional

1. decrease egocentrism
2. increase appropriate expression of feelings
3. increase feelings of self-worth/self-esteem
4. improve coping skills
5. reduce depression
6. reduce paranoid ideation

IV. Social

1. decrease isolation
2. increase communication skills
3. improve interpersonal relationships
4. improve family relations
5. increase social skills
6. increase utilization of social resources/supportive services
7. increase leisure skills

With the Plan developed, staff will then track participant progress toward the achievement of each objective. A daily notation file will be used for each participant. Support group notes will be kept. Other relevant experiences will be recorded. Routine progress notes will be written every two weeks to summarize level of functioning, changes in behavior, and weight/pulse/blood pressure readings. A monthly staff meeting will be scheduled to review formally the progress of each participant, with objectives updated, as appropriate.

The involvement of both the participant and family caregiver in the Individualized Program Planning process is critical. In addition to regularly scheduled meetings with family caregivers, activities of the Center will be made known through a newsletter. It will be sent to family caregivers and will include the monthly calendar of meals and special activities and outings. It should prove useful in augmenting conversation about Center activities.

It should also be noted that the testing of participants at 3-6-12-month intervals on those standardized tests/scales used for the initial assessment should provide valuable evaluative data for furthering the work of the Center and the sponsoring agency.

IV. STAFFING

A. General Qualifications

In recruiting staff for the Adult Respite Day Care Center, a number of qualifications must be considered. The applicant's concept of the position must be carefully reviewed. He/she must understand not only the work involved, but the level of physical and emotional stamina required. And, all employees must meet the medical requirements of the Commonwealth of Virginia.

All job finalists who have not had similar previous experiences will be asked to spend a day working in the program (or a similar program prior to this Center's initiation). This will provide an opportunity to observe the applicant's willingness: 1) to clean up and dress incontinent people; 2) to hand feed an entire meal; 3) to repeat instructions and tasks continually; 4) to rotate assignments; and 5) to comprehend and accept that two-way communication may never be established completely.

An uneducated applicant may be as effective as one with a graduate degree. Experience working with similar types of participants is considered as most valuable. Applicants must show evidence of flexibility, i.e., the ability to change directions and responsibilities quickly. Applicants must understand that working with program participants is difficult, in part, due to their mercurial nature, and the difficulty in understanding them. The job can be dirty, exhausting and demanding. Applicants must understand that participants will not get better because of their most sincere efforts. It clearly is not a job for everyone, no matter how well trained and educated.

Yet, despite the difficulties, applicants should be aware of the many satisfactions and rewards that come from this type of employment.

> The response of a person with dementia to an interested and caring individual is remarkable. The gratitude of families who are supported by caring staff is enormous. There is a reward in knowing that despite the inevitable consequences of progressive dementia, victims and their families are helped, family stability is maintained, and institutionalization is avoided, even for a brief period.[26]

All new staff will be hired for a 90-day probationary period to assure both parties that a proper fit has been made.

B. Staffing Pattern

Based upon our examination of several dementia day care programs, most notably the Harbor Area Center of Costa Mesa, California, and the Burke Rehabilitation Center of White Plains, New York, we have determined that a staff-participant ratio of 1-5 will be appropriate to provide the program envisioned. The use of volunteers, predominately drawn from ADRDA members, will reduce the ratio to 1-3.

The following staffing pattern is proposed for serving a daily participant group of 25.

- Director (full time)
- Assistant Director (full time)
- Program Assistants (two, full time)
- Office Assistant (half time)
- General Assistant (half time)

C. Position Descriptions

1. Director

- Requirements

  The Director of the program will be a professional having received an advanced degree in nursing, social work, gerontology, or a related field, and possess direct experience working with persons with Alzheimer's disease and related disorders. Knowledge and experience working with family caregivers is also required. An ability to relate well with relevant community resources, agencies, and a voluntary board of directors is also an important skill to possess. Skill in the organizational development of a membership organization is preferred. The Director must also be capable of conducting support group sessions and providing staff training and supervision, as required.

- Responsibilities

--Provide program and financial operating reports, as well as well-considered recommendations to the Board of Directors on a regular basis and as required;

--Provide orientation for new Board Members, as well as families of Center participants;

--Administer the Adult Respite Day Care Center within the policies set by the Board of Directors;

--Cosign checks with Board Treasurer and develop and maintain financial records, as necessary;

--Recruit, train, and supervise all program staff;

--Assist in fund raising by being available for public speaking and proposal development;

--Conduct support group sessions for program participants;

--Supervise the dispensing of medications in accordance with state and county regulations;

--Provide counseling for family caregivers, as needed;

--Maintain good relationships with other day care, health, and cooperative organizations;

--Provide a resource and operate as an advocate for persons with Alzheimer's disease and related disorders within the Northern Virginia area; and

--Perform other duties, as required.

2. Assistant Director

- Requirements

The Assistant Director of the program will be a professional in a discipline complementary to that of the Director which may include nursing, social work, gerontology, or a related field. In addition, he/she will possess direct experience working with persons with Alzheimer's disease and related disorders. An expertise in programming and activities relevant to persons participating in the program is essential. Experience working in an adult day care center is preferred. Relevant program planning and development skills are essential. Experience in leading activity groups is important, as is staff supervision and training. Possessing an ability to maintain schedules, records, track and assess individual progress toward goal achievement are necessary skills.

- Responsibilities

--Manage the daily activity program of the Center under the supervision of the Director;

--Supervise and train all activity staff (paid and volunteer);

--Conduct activity groups;

--Conduct admissions process;

--Create and maintain Individualized Program Plans for all program participants, making adjustments, in consultation with the Director and other staff, as required;

--Assist in the dispensing of medications in accordance with state and county requirements;

--Consult and advise particpants and family caregivers, as required; and

--Perform other duties, as assigned.

3. Program Assistants (2)

- Requirements

The two Program Assistants must possess either a degree in nursing, social work, gerontology, psychology, art therapy, recreational therapy, or a related field, or two years of successful experience in direct work with persons with Alzheimer's disease and related disorders, preferably both. Experience leading small activity groups in an adult day care center or similar setting is required. A range of specific skills in relevant activity areas, as well as the ability to be flexible in other areas, is important. The ability to work as a member of a team, under supervision, and maintain proper records is also necessary.

- Responsibilities

--Conduct activity groups, as assigned, under the supervision of the Assistant Director;

--Participate in the development and management of participants' Individualized Program Plans;

--Assist with daily activities such as drop off, snacks/ lunch, exercise, wrap up and departure, as assigned;

--Maintain records, as necessary; and

--Perform other duties, as assigned.

4. Office Assistant (half time)

- Requirements

The Office Assistant must be knowledgeable and personally familiar with the symptoms and characteristics of persons with Alzheimer's disease and related disorders and enjoy the benefits of providing support to them and their families. Experience working directly with persons with Alzheimer's disease and related disorders is preferred. Knowledge and successful experience in the full range of office skills (e.g., clerical, bookkeeping, record keeping, scheduling) are required. An ability to relate well to people and have flexibility is essential, as is the ability to work well in a team, under supervision.

- Responsibilities

--Manage the Center office under the supervision of the Director;

--Maintain office and participant records in an organized and confidential manner;

--Maintain roster of daily participation of staff and participants;

--Maintain financial records, including accounts receivable, payment of expenses, payroll and taxes;

--Prepare other necessary office-related materials, upon request;

--Assist with daily activities, such as drop off, snacks/lunch, wrap up and departure, as assigned; and

--Perform other duties, as assigned.

5. General Assistant (half time)

- Requirements

The General Assistant must be knowledgeable and personally familiar with the symptoms and characteristics of persons with Alzheimer's disease and related disorders and enjoy the benefits of providing support to them and their families. Experience working directly with persons with Alzheimer's disease and related disorders is preferred. A broad range of skills in program activity areas is essential to allow for flexible use in all areas of Center programming. An ability to relate well to people is essential, as is the ability to work well in a team, under supervision.

- Responsibilities

--Assist with any, and all, aspects of the Center program, as assigned, under the supervision of the Director;

--Conduct activity groups, as assigned, under the supervision of the Assistant Director;

--Assist with daily activities, such as drop off, snacks/lunch, toileting, exercise, wrap up and departure, as assigned; and

--Perform other duties, as assigned.

D. Volunteers

In order to allow for more individualized attention, supplementing personnel in the form of volunteers will be used to complement paid Center staff.

Recognizing that volunteers cannot be viewed as free labor or substitutes for paid staff, roles and responsibilities for them will be assigned only in non-essential areas. They will be viewed as luxuries and not as substitutes for necessities.

They will be treated as staff members, with position descriptions outlining specific responsibilities developed for each one. They will then be expected to carry out their assigned duties and receive supervision and training, in a manner similar to their paid counterparts. Also, as with paid staff, potential volunteers will be asked to spend a day in the program before a commitment is made.

The use of volunteers is considered a valuable experience for the program. They can add a freshness and variety to the Center thorugh the specific skills and interests which they may possess.

The use of family caregivers as volunteers will be strongly considered. This group will be most familiar with the needs and interests of the program participants and be experienced, as caregivers, in working with persons with Alzheimer's disease and related disorders. An added benefit is the cross-fertilization of techniques used by staff, and those successfully used at home by the caregivers, each learning from the other, all to the benefit of the program participants. Further, a consistant support effort between home and Center will do much to assist in the achievement of the treatment goals.

In addition, volunteers will be recruited for non-caregiving roles such as cleaning, painting, transporation, slide shows, music, art, pet therapy, and wherever other unique skills could be provided to participants.

Three volunteers per day will be recuirted to allow for enrichment of the program.

E. Staff Management

An evaluation and discussion of job performance between supervisor and staff member will be made every six months. The "Staff Evaluation" form used by the Harbor Area Center (Appendix R) will be considered as a format for such sessions.

In addition, a regular time will be allotted to in-service training for all staff and volunteers. Topics of mutual interest and need will be addressed.

V. FACILITY REQUIREMENTS

With the decision to create an Adult Respite Day Care Center comes the need to find suitable space for the program. In order for us to obtain the best facility which meets all the program needs, several factors must be examined. These have been grouped into the following areas: 1) licensing standards; 2) space considerations; 3) square footage needs; and 4) location. Each of these items is discussed below.

A. Licensing Standards

The information in this section comes from the Virginia Department of Welfare's Division of Licensing which is responsible for the care and protection of adults cared for on a regular basis outside of their own homes. Their jurisdiction includes adult day care centers. Their publication, "Standards and Regulations for Licensed Adult Day Care Centers," adopted in 1975 and amended in 1981, enunciates the standards which must be met by a facility in the Commonwealth of Virginia which is operating for profit.[27] Currently, no licensing standards are required for non-profit operators, although consideration is being given to expanding the coverage of the standards to non-profit operators. What is important to note is that the State's involvement in these matters is predicated on "the care and protection" of vulnerable groups. Therefore, the standards set are minimal--those required to assure the necessary care and protection only. They do not have a legal basis for quality of the program itself beyond these minimal concerns. Therefore, with our interests beyond those of the licensing requirements, and recognizing the potential of our facility to eventually be required to obtain a license to operate, the facility will be voluntarily operated in full compliance with the Virginia licensing standards set for such a facility. The most pertinent requirements are exerpted and included as Appendix S.

B. County Operating Permit

In addition to meeting the state requirements, there are those set by the County in which the facility is located. Consideration will be given to both Fairfax and Arlington Counties.

The beauty of the manner in which Fairfax County is organized is that it has developed a single procedure incorporating the requirements of several different offices. By submitting the required application to The Environmental Health Division of the Health Department, an applicant has only one agency with which to work. This office oversees the process of obtaining the required operating permit by forwarding copies of the submitted materials to the other public agency reviewing officials.

In Arlington County, the Office of Environmental Health also is the first place to contact. Their main concern is for food operations and the permit issued is a permit "to operate a food facility"--required even if meals are prepared elsewhere and brought to the Center. They (Mr. Glen Rutherford) advise that once a potential facility is selected that we draw up a "preliminary" set of plans which they will review with us. Such plans can be hand drawn to scale noting doors, kitchen, bathrooms, etc. At that time they will notify and advise us as to whether other govenrmental units will need to become involved. This will depend upon the changes required in the facility. Changes in plumbing, electrical, or moving a wall may require other governmental office reviews.

In Fairfax County two different roads may be taken depending upon whether a zoning variance is needed. Since the use of a facility for a different purpose requires at least a zoning variation, that road is most likely the one that will be required.

1. Obtaining a Zoning Variance

In Fairfax County the first concern is which category is most appropriate. The response to the letter (found as Appendix T) sent to Mr. Phillip Yates, Fairfax County Zoning Administrator, 10555 Main Street, Fairfax, VA 22050, will provide the answer as well as the specific requirements and steps to obtain the variance. Four months from the time of application must be expected until the decision on the variance request is made. Costs may be incurred if this process is required, including $300 for a public hearing, plus engineering fees for the development of a certified plat. (It is possible our selected facility will already have a plat and, therefore, not require these extra costs.)

In Arlington County Mr. Caffo, the Zoning Administrator, suggests 2-3 months may be required (advertising and posting notices for one or two public hearings) to obtain the necessary Use Permit. Such a permit is required for any facility with more than 25 people. A map of the County designating the current zoning is available from the Zoning Commission in the Arlington Courthouse. A C-2 "General Commercial" designation is the probable category. The County Board will make its decision on the zoning variance request at the public hearing.

2. Obtaining an Operating Permit

In Fairfax, if no zoning variance is needed, then the required operating permit can be directly obtained from the Fairfax County Department of Environmental Health. It will require four sets of detailed plans specifying items such as square footage, number of occupants, method of operation, floor plan to scale, site plan to scale, etc. The Department will coordinate the process by forwarding a copy to each of the reviewing offices (e.g., sanitation, fire marshall). (If a zoning variance is obtained, then only sketches are required by this office.) An estimated two months, if no major problems occur, can be expected before the plans are

are returned--either approved or noting necessary changes to be made. When the changes are completed, an on-site inspection will be made and if passed, a temporary operating permit will be granted at that time.

In Arlington, an application for a Certificate of Occupancy is obtained when the request for a zoning variance is made. The County Board will grant the Certificate after the public hearings are held.

C. Space Considerations

In addition to meeting the standards set by the State for licensure, several other space considerations must be considered in selecting a proper facility. These include the following, many of which were suggested by the Burke Rehabilitation Center.

1. Entrance and Exits

The shorter the distance between the point of arrival and the entrance, the better. A covered walkway or ramp will allow for a reliable and safe walking surface during poor weather.

2. Safety Concerns

Some potential hazards should be avoided. Glass doors or large windows which can be confused with thoroughfares should be avoided. Furniture with a protruding base is undesirable. Low stools and footrests should not be used. Sharp corners should be padded.

3. Bathroom(s)

These rooms should include toilet facilities usable by the handicapped, have space large enough for changing soiled clothes, have equipment to wash and clean incontinent participants, possess locked cabinets for storage of first aid supplies, clean washrags, and antiseptic soap. They should be located in close proximity to activity areas.

4. Access to Outside

There could be an outside area which can be used all year. Everyone needs an area to walk and exercise, but a visual barrier is needed to prevent wandering. This would be a low fence or suitable shrubbery. The addition of outside chairs or benches would be useful.

5. Quiet Room

Occasionally, it will be necessary to move a participant away from the mainstream of activity. A small, quiet room for calming an agitated person which will prevent the spread of anxiety is important. It is useful for this area to have equipment to monitor vital signs. This room can also offer privacy for staff and participant or family conferences.

6. Kitchen

A kitchen is useful in reinforcing skills of daily living. It is especially important during holidays and birthdays. It should have a lockable refrigerator, a stove, sink, and a storage area (locked if drugs are kept there). It is not to be used for preparing lunches, but will be used for snacks.

7. Furniture

All furniture needs to be functional and movable. Recliners can be used by those who need rest periods built into their Individualized Program Plans. Large fabric chairs are to be avoided because they are easily soiled or wet. A collection of small tables, rather than one large table, will provide more versatility.

8. Storage and Office Space

A variety of items need to be locked. A large walk-in closet is best. Each staff person will need a desk and locker. Patient records must be kept in locked files to insure confidentiality.

9. Warning Systems

A bell or buzzer should be placed in toilets to summon help when needed.

10. Fire Protection

Fire extinguishers will be placed in the kitchen and activity areas and staff trained in their use. Fire drills will be conducted with both staff and participants. Smoke alarms also will be used.

D. Square Footage Needs

After consultation with several directors of similar programs, an estimate of 100 square feet of indoor space per program participant is considered optimum for conducting the proposed program. In addition, outdoor space to allow for supervised walking and other recreational activities will be provided. For the estimated 25 participants, a facility with 2,500 square feet would be suitable. In considering the needs discussed above, the following break-out is advisable:

• Activity area	1,500	square	feet
• Staff offices and storage area	400	"	"
• Bathrooms	200	"	"
• Kitchen	150	"	"
• Quiet room/conference room	150	"	"
• Transition room/entrance hall	100	"	"
Total	2,500	square	feet

E. Location Requirements

Recognizing that the ADRDA service area covers all of Northern Virginia, a facility centrally located would be the fairest means of sharing the driving responsibilities of all participant families. A facility at either end of the area would clearly place undue hardship on those living at the far end of the service area.

F. Types of Facilities

After examining the licensing standards, space considerations, square footage needs, and location requirements, we are prepared to investigate the options available for a day care center facility. Obviously our search must also consider a facility which does not require a major expenditure of funds to convert it to our program needs. Among the types of buildings to examine are the following:

- Vacant and available school buildings;
- Leasable church facilities with unused space during the day hours;
- Public buildings with vacant space during the day hours;
- Privately donated building space; and
- Private organization buildings with space unused during the day hours.

VI. LEGAL CONCERNS AND LEGAL PROTECTIONS

A. Sponsorship of the Center Program

Several suggestions have been made by ADRDA members regarding the auspices under which the Day Care Center should be operated. Some members have assumed it would become a program under the ADRDA Board Chapter Board; others have suggested a new non-profit corporation be created; and some have asked that we investigate the creation of a new organization--a cooperative owned by the members.

Proposed is the creation of a newly chartered non-profit membership corporation under the laws of Virginia, with the basic democratic control and ownership principles of a consumer-owned cooperative included in its articles of incorporation.

This assumes that families with participant members own the cooperative and, through membership meetings and an elected board, establish its basic policies.

Among the basic cooperative principles are the following:

1. One vote per member with no proxies;
2. Limited or no return on member investment;
3. Open membership--no restrictions due to race, religion, etc.;
4. Non-partisan in political activities; and
5. Net savings either retained in the business operation or distributed to members in proportion to the use of the services.

This new non-profit cooperative adult day care center will include on its board of directors those elected by and from the participating support families; and those named from the general public who have needed expertise; and those from the Alzheimer's Disease and Related Disorders Association of Northern Virginia. The exact number from each category will be determined.

A mechanism will be devised to allow contributors to the new cooperative to deduct their donations from their taxable income.

Appendix U contains a draft of the Articles of Incorporation and By-Laws from the new sponsoring organization.

B. Insurance Requirements

A variety of types of insurance will be purchased to minimize the risk of liability and loss. These are included below with dollar estimates based upon the information available today.

	Year
● Workman's Compensation --based on payroll	$ 200
● General Liability --based on the facility used; contents coverage, plus $500,000 liability coverage	700
● Professional Liability (Malpractice) --costs dependent on Director's education and training; all staff and volunteers are covered; $1 million coverage	500
● Catastrophic Liability (Umbrella Policy) --$10 million coverage; covers after the $500,000 general liability limits are met	1500
● Fidelity Bond --$10,000 bond	100
Total Costs	$3000/yr. $250 /mo.

C. Participating Family-Center Agreements

The following agreement will be utilized by the sponsoring agency for the Center and the Center's participating families:

AGREEMENT

AGREEMENT between (name of sponsoring agency), known as the "Sponsor" of "The Adult Respite Day Care Center" and (person designated as responsible family caregiver), for the "Participant," a family member with Alzheimer's disease or a related disorder.

1. SERVICES. By signing this Agreement, the designated responsible family caregiver is entitled to have a family member with Alzheimer's disease or a related disorder participate in the Center program.

2. TERM. Attendance in the Center program will continue as long as the monthly fees are paid. Family caregivers may terminate Participant involvement by writing to the Center at least ten calendar days before the termination is to be effective. However, if a Participant's circumstances change unexpectedly, or are beyond control, the Center may waive such notice.

   The Center reserves the right to discontinue the provision of service through a written ten-calendar day notice if at any time it is determined the Center can no longer provide the support appropriate to the Participant's needs.

3. FEES. Responsible family caregiver shall pay an Initiation Fee of $50.00 when this Agreement is signed and before services are rendered. The Initiation Fee shall cover the cost of the initial interview and the preparation of the Participant's Individualized Program Plan. (The Individualized Program Plan is a detailed analysis of the Participant's needs and interests for specific support services, and a program for supporting the Participant's interest in functioning as independently as possible.) The Initiation Fee is non-refundable and may not be transferred or assigned to someone else.

In exchange for receiving the Center benefits, the responsible family caregiver shall also pay a monthly fee of $________ for ____ days of Participant care per week.

Fees for Center services shall not be changed for at least six months, and thereafter may be changed no more than once every year.

The Center shall send an invoice for the monthly fee to the responsible family caregiver by the 15th of each month. The family caregiver shall pay the bill by the fifth day of the next month, or a late payment fee of 1.5% of the unpaid balance will be added to the next monthly bill. Center attendance may be terminated if fees are not paid for two consecutive months.

4. MEDICAL INFORMATION AND AUTHORIZATION. The responsible family caregiver shall be responsible for informing the Participant's personal physician of the activities in which the Participant will be involved while in attendance at the Center. The responsible family caregiver will take full responsibility for obtaining a written statement from the Participant's personal physician which describes any and all medical, physical, emotional, or dietary restrictions that may adversely affect full participation in Center activities. Such written notification shall be accomplished through the completion of the "Medical, Physical, Emotional, and Dietary Restrictions" form found as Exhibit I to this Agreement. Further, the responsible family caregiver shall be responsible for informing the Center in writing of any and all changes in his/her physical, medical, emotional. or dietary condition which may affect Participant involvement in Center activities. The responsible family caregiver shall attest to such agreement by affixing his/her signature to Exhibit I which shall hereby become a part of this Agreement.

The Center reserves the right to refuse Participant involvement in certain Center activities without prior written approval from the Participant's physician.

The responsible family caregiver authorizes the Center to seek emergency medical assistance on the Participant's behalf, if such a need becomes necessary.

5. LIMITATION OF LIABILITY. All staff used by the Center are experienced in working with elderly persons. All have been carefully screened. All have received pre-service training and are regularly supervised by a registered nurse. The Center will not be liable for any incidental or consequential damages arising from delay or non-performance of any service under this Agreement. The Center will not be liable for any damages due to circumstances beyond its control.

6. ARBITRATION. In the event of any dispute or claim under this Agreement, the matter shall be submitted to binding arbitration in accordance with the local rules of the American Arbitration Association. This provision shall not apply to claims for collection of unpaid monthly membership fees unless the responsible family caregiver has notified the Center in advance that they desire to arbitrate such a claim.

IN WITNESS WHEREOF, the parties have executed this Agreement this __________ day of _________________, 19_____.

WITNESS:

____

RESPONSIBLE FAMILY CAREGIVER: (for Participant)

____
(Signature)

____
(Print Name)

____
(Name of Participant)

____
(Address)

____
(Telephone)

(Name of New Sponsoring Agency)

____
(Signature)

____
(Print Name and Title)

EXHIBIT I

MEDICAL, PHYSICAL, EMOTIONAL, AND DIETARY RESTRICTIONS

The following medical, physical, emotional, or dietary restrictions may have an effect on the Participant's involvement in Center activities:

I agree to notify the Center of any and all changes in the Participant's medical, physical, emotional, and dietary conditions which may affect his/her involvement in Center activities.

____
(Signature of responsible family caregiver)

____
(Participant name)

____
(Date)

VII. BUDGET

A. Start Up Costs

A number of items will need to be obtained before the program can begin. The costs associated with these items are one-time costs and, therefore, are not calculated within the Center Operating Budget. Included in the anticipated start-up costs are the following:

• Legal incorporation fees	$ 500
• Printing --stationery ($250) --brochures ($1000)	1,250
• Furniture and other furnishings	5,000
• Rental and phone deposits	750
• Renovations	2,500
Total Start-up Expenses Anticipated	$10,000

Income from non-participant sources (unless a one-time sign-up fee is created) will be used to cover these one-time costs. Some items, like furnishings, may be obtained through donation, thus reducing the start-up cost requirement.

B. Initial Monthly Deficits

In addition to these one-time start-up costs, adjustments must be made to account for the reduced daily attendance (and, therefore, income) during the initial months of the Center's operation.

In anticipation of the lower daily attendance, some operating expenses will not be encumbered upon the opening of the Center. The following operating budget adjustments will be made during the initial months.

- The full complement of staff will not be hired until the full complement of daily participants is achieved.

Staff will be added in accordance with the 1-5 ratio of staff-participants. This also will allow for less costs incurred in payroll taxes and fringe benefits; and

- Costs for consumable items used by participants, such as meals and activity materials, also will be reduced.

Monthly deficits from the time the Center opens until daily attendance reaches an average of 20 are expected for the first four months of operation. These are displayed on the "Monthly Cash Flow Projections" chart that follows. In sum:

● Month 1	-$2,553	
● Month 2	- 1,323	
● Month 3	- 647	
● Month 4	- 316	
	-$4,839	Total Deficit Expected

C. Costs of Director Prior to Center Opening

The hiring of the Center Director on a quarter time basis to provide the leadership in the developmental activities required for the program's initiation, as well as to work with the new Board in its development and training is also anticipated. The costs involved are displayed as follows:

● Salary	$500/month x 4 months	$2,000
● Fringes	$100/month x 4 months	400
● Payroll Tax	$66/month x 4 months	264
	Total Costs	$2,664

D. Summary of Funding Needs

When the anticipated Monthly Deficits ($4,839) are added to the anticipated one-time Start-Up Costs required ($10,000), and the costs of the Director prior to the Center's opening ($2,664) are added, a total cost of $17,503 will be required until the program becomes self-supporting.

Obviously, donations (e.g., free rent for the facility or furniture) would reduce costs considerably.

Monthly Cash Flow Projections - Start Up

		Month					
		(1)	(2)	(3)	(4)	(5)	(6)
I.	Average Daily Partic. Anticipated	3	6	10	15	20	25
II.	Expenses Anticipated						
	Direct Labor						
	Director	$1000	$1000	$1000	$2000	$2000	$2000
	Assistant Dir.	-	-	333	667	667	1333
	Prog. Assist. (2)	500	500	1000	1000	1500	2000
	General Assist.	-	-	-	-	-	500
	Office Assist.	500	500	500	500	500	500
	Fringe @10% DL	200	200	283	417	467	650
	Payroll Taxes @6% of DL	132	132	165	281	314	429
	TOTAL DL	$2332	$2332	$3281	$4865	$5448	$7395
	Other Direct Costs						
	Telephone	50	50	50	75	75	100
	Office Supplies	10	10	10	20	20	25
	Meal Prep. Service @$2/meal	200	280	400	600	800	1000
	Insurance	250	250	250	250	250	250
	Accounting	42	42	42	42	42	42
	Attorney	83	83	83	83	83	83
	Rent	625	625	625	625	625	625
	Utilities and Main.	156	156	156	156	156	156
	Activity and Part. Consumable Mater.	25	35	50	75	100	125
	Printing and Postage	50	50	50	75	75	100
	Publicity	50	50	50	50	50	50
	TOTAL ODC	$1541	$1631	$1766	$2051	$2276	$2556
	TOTAL EXPENSES ANTICIPATED	$3873	$3963	$5047	$6916	$7724	$9951
III.	Income Anticipated from Participants	$1320	$2640	$4400	$6600	$8800	$11000
IV.	TOTAL DEFICIT ANTICIPATED	-$2553	-$1323	-$ 647	-$ 316	+$1076	+$1049

E. Costs of Operating the Program - Operating Budget

The following costs will be incurred in the operation of the program for an average daily attendance of 25 participants.

	Month	Year
Expenses		
● Direct Labor		
Director	$ 2,000	$24,000
Assistant Director	1,333	16,000
Program Assistants (2 @$12,000/year)	2,000	24,000
General Assistant (½ time @$12,000/year)	500	6,000
Office Assistant (½ time @$12,000/year)	500	6,000
	$ 6,333	$76,000
Fringe @10%	633	7,600
Payroll Taxes (Social Security, Unemployment, income @6% of DL)	429	5,148
TOTAL DIRECT LABOR	$ 7,395	$88,748
● Other Direct Costs		
Telephone	100	1,200
Office Supplies (consumable)	25	300
Meal Preparation Service ($2 per meal)	1,000	12,000
Insurance	250	3,000
Accounting	42	500
Attorney	83	1,000
Rent, Utilities & Maintenance	781	9,375
Activity and Participant Consumable Materials (@ .25/part./day)	125	1,500
Printing and Postage	100	1,200
Publicity	50	600
TOTAL OTHER DIRECT COSTS	$2,556	$30,675
TOTAL EXPENSES	$9,951	$119,423

F. Income

If we assume an average daily attendance of 25 participants x 20 days of service per month, we can calculate 500 participant days/month of service. When we divide the $9,951 monthly operating costs into the 500 participant days of service, we note a daily cost of $19.90 for each participant day of service. A charge of $22 per participant day of service, allowing for some unexpected expenses and the potential use of sponsorship for those who may not be able to afford the costs, appears to be appropriate. In addition, if two weeks a year are to be used for staff training and planning while the Center is closed, then a loss of revenue ($22/day x 25 participants x 10 days = $5,500) must be expected. This charge is similar to that of most other similar programs operating elsewhere in the country, as well as those other adult day care programs operating in Northern Virginia.

G. Sources of Income

The source(s) from which the program operating costs are gathered present options for consideration. For example:

- Charge participants full fee for the costs of service (i.e., $22/service day); or
- Charge participants less than full fee and supplement the deficit from other sources, or from surplus program revenues.

Among the other potential sources of revenue to be considered are the following:

- Service, religious, or business organizations which may be interested in supporting this cause (e.g., Knights of Columbus, Chamber of Commerce, church groups);
- Individual or corporate tax-deductable donations solicited through a program of deferred giving or memorials;

- The creation of a "sponsorship" program sold through a fundraising campaign to interested individuals and corporations (e.g., $5,280 will allow someone to become a full sponsor which will allow one participant to attend the Center full time for one year);

- Government research and/or demonstration program funds may be available for this unique program designed to meet the needs of a growing national problem (e.g., The National Institute of Mental Health, Aging Division, currently is interested in supporting projects on Alzheimer's disease); and

- Foundations concerned with the elderly may find this unique program of interest to them (e.g., MacArthur Foundation, Johnson Foundation, and locally the Stern Family Fund).

Some sources may be attracted to the subsidizing of particular budget items such as providing the facility at no or minimum cost, contributing activity materials, furniture, or free printing costs.

For each dollar obtained through an outside source, the operating costs shared by participants can be lowered by that amount.

VIII. IMPLEMENTATION SCHEDULE

The following milestone chart provides a listing of those activities and dates required to open the Adult Respite Day Care Center by May 1, 1984.

In order for this goal to be accomplished, the time and effort of many ADRDA Northern Virginia Chapter members will be required under the leadership of the Chapter President and Executive Committee.

The tasks to be accomplished have been clustered into three significant areas:

- New Board development/director recruitment;
- Obtaining a facility; and
- Fundraising.

It should be noted that in case a facility can be obtained which does not require the lengthy zoning variance process, and the required start-up costs can quickly be obtained, a significantly earlier facility opening could be expected.

MILESTONE CHART

DESCRIPTION	NOV 83	DEC 83	JAN 84	FEB 84	MAR 84	APR 84	MAY 84
II.Fundraising							
Review start-up funding needs		△					
Develop fundraising strategy		△—△					
Develop list of sources of fund.		△					
Send proposals to governmental and foundation sources			△				
Make presentations to service, religious, business org.			△—	—	—	—	△
Publicize donations, sponsorship			△—	—	—	—	△
Recruit participants					△—	—	△

MILESTONE CHART

DESCRIPTION	NOV 83	DEC 83	JAN 84	FEB 84	MAR 84	APR 84.	MAY 84
I.New Board Devel./Dir.Recruit.							
Review Articles of Incorp.,By-laws & potential Board members	△						
Meet with Attorney to finalize Articles of Incorp. & Bylaws	△						
File for incorporation		▲					
Invite members to join Board		▲					
Develop job descrip.for Director		△					
Advertise for Director		△					
Screen candidates for Director		△	△				
Hire Director - ½-time			▲				
Develop agenda & schedule Board training		△					
Conduct Board training sessions			△				△
II.Obtaining Facility							
Review facility requirements		△					
Visit potential facilities/ Determine modifications req'd.		△	△				
Select 1st choice facility			△				
Develop sketch of facility with modifications required			△				
Meet w/County Environ.Hlth.Dept			△				
Meet w/State licensing official			△				
Meet w/County Zoning Adminis.			△				
Determine adequacy of facility w/required modifications			△				
Make application for zoning variance & use permit				▲			
Make alterations in facility				△	△		
Prepare for public hearing(s)				△ △			
Obtain operating permit							▲
Obtain licensing inspection							▲

FOOTNOTES

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7. Ibid., p. 7-8

8. Ibid., p. 23.

9. Ibid., p. 23.

10. Ibid., p. 24.

11. Ibid., p. 24.

12. Weiler, Philip G. and Rathbone-McCuan, Eloise. Adult Day Care; Community Work with the Elderly. New York, NY. Springer Publishing Company, 1978, p. 6-7.

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25. Panella, *Op. Cit*., p. 17.

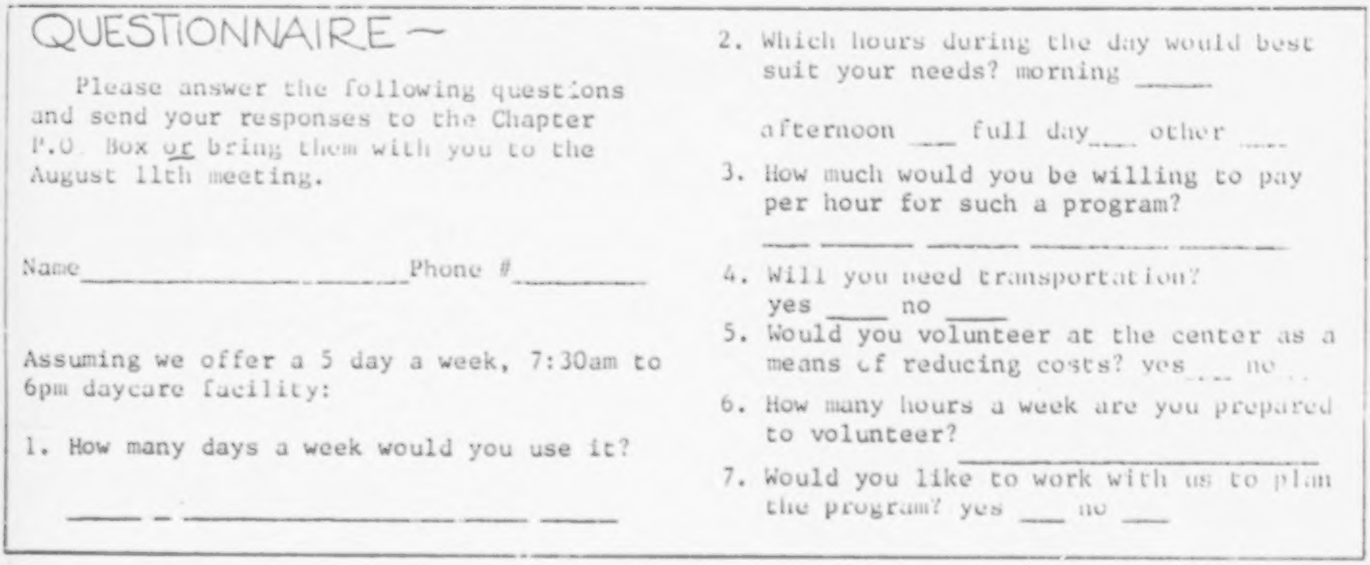
26. *Ibid*., p. 5.

27. *Standards and Regulations for Licensed Adult Day Care Centers*. Richmond, VA: Virginia Department of Welfare, 1975.

APPENDICES

APPENDIX A

ADRDA/No. Va. Membership Questionnaire



QUESTIONNAIRE ~

Please answer the following questions and send your responses to the Chapter P.O. Box or bring them with you to the August 11th meeting.

Name_______________________Phone #_________

Assuming we offer a 5 day a week, 7:30am to 6pm daycare facility:

1. How many days a week would you use it?

_____ _ ____________________ _____ _____

2. Which hours during the day would best suit your needs? morning _____

afternoon ___ full day___ other ___

3. How much would you be willing to pay per hour for such a program?

____

4. Will you need transportation?
yes _____ no _____
5. Would you volunteer at the center as a means of reducing costs? yes___ no __
6. How many hours a week are you prepared to volunteer?
____
7. Would you like to work with us to plan the program? yes ___ no ___

APPENDIX B

Physician Approval for Participation

TE OF CALIFORNIA – HEALTH AND WELFARE AGENCY

DEPARTMENT OF SOCIAL SERVICES

YSICIAN'S REPORT

ident of, or applicants for
sion to, Community Care Facilities

(NAME AND ADDRESS OF CARE FACILITY)

HARBOR AREA ADULT
DAY CARE CENTER
661 West Hamilton
Costa Mesa, CA 92627
(714) 548-9331

OTE TO PHYSICIAN:

he person whose name appears below is a resident of, or an applicant for admission to, a licensed community care facility. hese facilities provide the personal care and supervision normally provided by a relative to a member of the family. A urrent health report is required on each person in the facility.

OMMUNITY CARE FACILITIES DO NOT PROVIDE PROFESSIONAL NURSING CARE.

NAME

2. PRESENT ADDRESS

AGE

4. SEX

5. DATE OF EXAMINATION

6. LENGTH OF TIME UNDER YOUR CARE

7. SOCIAL SECURITY NUMBER

DIAGNOSIS

MAJOR

OTHER

TUBERCULOSIS EXAMINATION: ☐ ACTIVE OR QUIESCENT ☐ INACTIVE OR NONE

HOW DETERMINED

DATE

OTHER CONTAGIOUS OR INFECTIOUS DISEASES

☐ NONE IF ANY, SPECIFY

HEALTH

PHYSICAL HEALTH

GENERAL HEALTH
☐ GOOD ☐ FAIR ☐ POOR

AUDITORY IMPAIRMENT
☐ NONE ☐ MILD ☐ SEVERE

VISUAL IMPAIRMENT
☐ NONE ☐ MILD ☐ SEVERE

SPECIAL DIET (SPECIFY)

ALCOHOLIC PROBLEM
☐ NONE ☐ OCCASIONAL ☐ FREQUENT

MENT:

MENTAL CONDITION

	YES	NO
	(CHECK ONE)	
17. Clear		
18. Confused part of the time		
19. Confused all or most of the time		
20. Able to follow orders		
21. Depressed		

CAPACITY FOR SELF-CARE

	YES	NO
	(CHECK ONE)	
Is able to care for all personal needs		
Can administer own medication		
Needs help with medication		
ication prescribed and instructions given atient (specify)		

	YES	NO
	(CHECK ONE)	
26. Bathe self		
27. Dress self		
28. Feed self		
29. Care for toilet needs		

C 602 (1/80)

(Over)

REQUIRES ASSISTANCE FOR:

	YES	NO		YES	NO
	(CHECK ONE)			(CHECK ONE)	
ting out of bed			34. Bladder control night		
Walking			35. Bladder control day		
Using crutches			36. Bowel control		
Using wheelchair					

PROFESSIONAL NURSING CARE NEEDS

	YES	NO		YES	NO
	(CHECK ONE)			(CHECK ONE)	
Requires continuing bed care			39. Frequency and amount of medicine determined on the basis of daily professional observation of symptoms or laboratory tests		
Requires the administration of medicines not safe for self–administration			40. Needs constant medical supervision		

ER SPECIAL TREATMENTS OR NURSING PROCEDURES (SPECIFY – E.G. – OXYGEN – INDWELLING CATHETER, ETC.)

PORTANT:

your opinion is the person mentally and physically capable of leaving the building without assistance in an emergency?

Yes ☐ No · If No, explain:

YSICIAN'S NAME (TYPE OR PRINT)	ADDRESS	TELEPHONE
GNATURE OF PHYSICIAN ▶		DATE

(Use this section if additional space is needed.)

AUTHORIZATION FOR RELEASE OF MEDICAL INFORMATION

hereby authorize the release of medical information contained in the report of the examination of

(SELF, OR STATE NAME OF PERSON AND RELATIONSHIP)

o

(NAME AND ADDRESS OF AGENCY, INSTITUTION, HOME REQUESTING INFORMATION)

HARBOR AREA ADULT
DAY CARE CENTER
661 West Hamilton
Costa Mesa, CA 92627
(714) 548-9331

medical information is required to assist the above–named agency in determining the type of care needed.

IGNATURE ▶	DATE	ADDRESS

23701-010 9-81 85M - OSP

APPENDIX C Release of Information and Initial Referral Sheet

HARBOR AREA ADULT DAY CARE CENTER

1. Name of CLIENT: ______________________________

ADDRESS ______________________________

____

2. Name of Family Member or Contact: ______________________________

Address ______________________________

____

INFORMATION:

Age: ____________ Present Living Situation ____________

Why interested in Day Care? ______________________________

____

Date of Interview: ____________ Date of Admission to Program ____________

Release sent to Physician ____________ Applied for Financial Assistance ____________

Approved for Financial Assistance ____________

Other Comments or Information :

APPENDIX D

Client Record Data Base

HARBOR AREA ADULT DAY CARE CENTER

DATA BASE

Client Record

1. Name ______________________________
   Address ______________________________
   Telephone ______________________________
2. Emergency Contact (Name) ______________________________
   Address ______________________________
   Telephone ______________________________ Relationship ______________
   Place of Employment ______________________________
   Telephone (Work) ______________________________
3. Physician's Name ______________________________
   Address ______________________________ Phone ______________
4. **Medical Section**

   A. History of surgeries, diseases, health problems

   B. Current Health status
      1. Diagnosis
      2. Medications and Dosage
      3. Activity Restrictions
      4. Health aids (Glasses, hearing aid, dentures, braces, pacemakers, etc.)
      5. Diet

   C. Psychiatric History: Affective/Behavioral
      Suicide attempts; significant aggressive behaviors; depression. Ask extent of involvement, halucinations, delusional, feels persecuted, etc.

Client Record, cont.

5. Current Social Assessment

A. Living Status
    Does client live alone?
    Describe degree of independence
        (a) mobility
        (b) cooking
        (c) laundry

B. Describe family support network and losses.

C. Describe peer relationships, community participation (church, social, recreational)

D. Source of referral to Day Care Program and alternatives explored.

E. Applicant's motivation for participation

6. Other information: Client's special interests and talents

7. Problems from Outreach Worker's View:

signed: Interviewer

APPENDIX E

SOUTH COAST INSTITUTE FOR APPLIED GERONTOLOGY
HARBOR AREA ADULT DAY CARE CENTER
COMMUNITY VOLUNTEERS FOR THE ELDERLY
661 W. HAMILTON STREET
COSTA MESA, CA 92627
714 548 [illegible]
714 [illegible]

EMERGENCY PROCEDURE

In case of any change in behavior or physical condition perceived by the staff to require immediate medical attention, our policy is to:

1. Call the paramedics
2. Call the client's physician
3. Call the family

If hospitalization is necessary, paramedics will bring the client to Costa Mesa Memorial Hospital, unless directed otherwise.

I understand and agree with the above procedure.

____
Name

____
Date

APPENDIX F

Patient Interest Profile

Occupation ____________ Birthday ____________ Age ____________

Years of School ____________ Religion ____________

Visitors ____________

Special Diet ____________

Diagnosis ____________

Bed Care ____

Wheelchair ____

Ambulatory ____

Ambulatory with walker ____

Ambulatory and wheelchair ____

APPLICABLE

Limited [illegible] of hands ____

None of these handicaps ____

EXTREMELY Disoriented

(Non communicative) ____

Confused at times ____

PERSONAL ORIENTATION

- ☐ Distinguishes between past and present events
- ☐ Is over concerned with self
- ☐ Is content concerning self
- ☐ Is content in environment
- ☐ Is aware of surroundings and needs
- ☐ Responds to meaningful moments
- ☐ Has a religious orientation
- ☐ Is generally happy
- ☐ Accepts personal limitations
- ☐ Desires to be useful
- ☐ Is concerned for personal dignity
- ☐ Seeks personal satisfaction in achievement
- ☐ Desires recognition of individuality
- ☐ Generally thinks constructively
- ☐ Has confidence in others
- ☐ Has natural curiosity
- ☐ Holds positive attitudes

RELATIONSHIPS

- ☐ Prefers to be alone
- ☐ Participates well in group experiences
- ☐ Wants to help others
- ☐ Seeks out companionship
- ☐ Reacts well to competition
- ☐ Is able to accept others
- ☐ Reacts in hostile manner to others

INTERESTS AND HOBBIES

- ___ Music
- ___ Weaving
- ___ Knitting
- ___ Crocheting
- ___ Sewing
- ___ Word Games
- ___ Creative Writing
- ___ Fishing
- ___ Card Games
- ___ Sports
- ___ Cooking
- ___ Gardening
- ___ Photography
- ___ Reading
- ___ Painting
- ___ Ceramics
- ___ Puzzles

Table Games:

- ___ Bingo
- ___ Checkers
- ___ Chess
- ___ Yahtzee

Other ____

COMMENTS: ____________

TYPES OF NEEDED ACTIVITIES

- ___ Physical exercise
- ___ Entertainment
- ___ Competition
- ___ Communication
- ___ Meaningful work
- ___ Educational stimulation
- ___ Creative expression
- ___ Community involvement
- ___ Self care
- ___ Social inter-action
- ___ Service to others
- ___ Sensory stimulation
- ___ Health maintenance
- ___ Release of tension
- ___ Leadership involvement
- ___ Emotional expression
- ___ Spiritual encounter

GOALS OF ACTIVITY PLAN

- ___ Remotivation
- ___ Socialization
- ___ Prevent preoccupation
- ___ Learn new skills
- ___ Increase attention span
- ___ Restore feeling of self worth
- ___ Reduce incontinency
- ___ Promote a healthy life style
- ___ Reduce overt self-pity
- ___ Mood elevator
- ___ Reduce confusion
- ___ Promote good personal habits
- ___ Reduct psychological regression
- ___ Acceptance of personal limitations
- ___ Satisfaction and contentment with environment

SELF CARE ACTIVITIES: IF PATIENT IS TO BE INVOLVED IN SELF CARE AND WORK RELATED ACTIVITIES, CHECK THOSE THAT ARE TO BE USED:

- Make own bed ___
- Clean Room ___
- Dress self ___
- Shower self ___
- Fold linen ___
- Deliver Mail ___
- Gardening ___
- Straighten library ___
- Other ____________

Signed ____________

Date ____________

PHYSICIAN: *PLEASE READ AND SIGN*

I have read and approve the activity treatment plan for Mr Ms. ____________ or see signed Dr.'s. Orders ☐

The activity plan can be followed except for the following restrictions: ____________

This patient can: (PLEASE CIRCLE)

Yes No Leave the facility to go on field trips.

Yes No Have (on occasion) an alcoholic beverage)

Yes No Participate in self care and work related activities.

PATIENT INTEREST PROFILE

SIGNED ____________ DATED ____________

ARTISTIC PRESS

FORM 3325

APPENDIX G

Name ____________________

Activities of Daily Living

(Mark one only)

. TOILET

_____1. Cares for self at toilet completely, no incontinence

_____2. Needs to be reminded or needs help in cleaning self, or has rare (weekly at most) accidents

_____3. Soiling or wetting while asleep more than once a week

_____4. Soiling or wetting while awake more than once a week

_____5. No control of bowels or bladder.

B. FEEDING

_____1. Eats without assistance

_____2. Eats with minor assistance and is untidy, needing help cleaning up

_____3. Eats with minor assistance for all meals

_____4. Requires extensive assistance for all meals

_____5. Does not feed self at all and is uncooperative with others feeding him/her

C. DRESSING

_____1. Dresses, undresses and selects own clothing-needs no assistance

_____2. Needs minor assistance sometimes, but for the most part can dress and undress

_____3. Needs some moderate assistance always in dressing and undressing

_____4. Needs major assistance, but cooperates with efforts of others to help

_____5. Needs major assistance, and resists efforts of others to help

D. GROOMING (neatness, hair, face, hands, nails, etc.)

_____1. Always acceptably groomed without assistance

_____2. Needs minor assistance in grooming, and occasional reminders.

_____3. Needs regular supervision or assistance in grooming

_____4. Needs total grooming care, but remains interested in staying well-groomed

_____5. Needs total grooming care, but is not interested in maintaining grooming; sometimes resists and negates efforts of others

E. BATHING

_____1. Bathes self without help

_____2. Bathes self with help getting in and out of tub or shower

_____3. Bathes self with little assistance, but needs to be reminded to bathe.

_____4. Needs to be bathed by others, but cooperates

_____5. Needs to be bathed by others, but resists and refuses to cooperate

F. AMBULATION

_____1. Walks unassisted usually

_____2. Walks with only arm or railing or chair for support, usually; or walks with a walker

_____3. Walks if given substantial support

_____4. Moves self around in wheelchair, can get in and out alone

_____5. Moves self around in wheelchair, must be lifted in and out

_____6. Must be pushed around in wheelchair

G. ACTIVITY

_____1. Gets out of bed and dressed in morning, remains out until bedtime with one nap, at most, during day

_____2. Gets out of bed in morning, but naps off and on through day

_____3. Gets out of bed if reminded

_____4. Gets out of bed if reminded and assisted

_____5. Gets up only when forced, then spends most of day out of bed

_____6. Spends whole day in bed, could be out more often

_____7. Spends whole day in bed, too sick to get out.

H. EYESIGHT

_____1. Normal or better

_____2. Slightly impaired; can read, but for limited time periods

_____3. Somewhat impaired; can read large print, see movies, etc.

_____4. Considerably impaired; unable to see well enough to read, but can distinguish faces, etc.

_____5. Functionally blind

I. HEARING

_____ 1. Normal or better

_____ 2. Slightly impaired; occasionally asks "what", etc.

_____ 3. Somewhat impaired; hears about half of what is said to him, does not hear others' conversations well

_____ 4. Considerably impaired; has great difficulty hearing.

_____ 5. Functionally deaf.

J. SPEECH (Quality of speech, not content or meaning)

_____ 1. Normal or better

_____ 2 Slightly impaired; may give brief response to repeated question

_____ 3. Slightly impaired; at times garbled

_____ 4. Somewhat impaired; one must concentrate; hard to understand

_____ 5. Considerably impaired; one can only pick out occasional words; or person speaks in fragments, only expressing needs, etc.

_____ 6. Mute; or impossible to understand

APPENDIX H

HARBOR AREA ADULT DAY CARE CENTER

Group Exercise Program for Seniors

1. Neck Circles: make slow circles letting your neck really stretch.

2. Shoulder Rotations: make circle using both shoulders.

3. Arm Lifts: hold your involved arm acroes your body and lift up and out.

4. Arm Chops: hold your involved arm at your side and lift up and across your face.

5. Pronation/Supination: place hands on your lap, palms up. Now turn them down. If not possible use the good hand to help out the involved one.

6. Finger ROM: open your fingers as wide as possible and then close tightly. You can help out with the other hand.

7. Trunk Rotation: with arms crossed in front of you, touch your right elbow to your left knee. Straighten and then touch the left elbow to the right knee.

8. Rock the Baby: cross your arms in front of you and rock them back and forth as if rocking a baby.

9. Elbow Lifts: with arms crossed, lift both elbows way up and over your head.

10. Marching in Place: while sitting lift first one knee, then the other as high as possible so you're marching in place.

11. Toe Touches: sitting, bend at the waist and touch your toes. Straighten and repeat.

12. Upper Extremity Reciprocation: lift first the right arm over the head as far as possible then the left. Alternate back and forth.

13. Upper Extremity and Lower Extremity Reciprocation: lift left knee and right arm up. Then repeat with the right knee and left arm. Alterante back and forth.

14 Diaphragmatic Breathing: place one hand on your stomach right below your ribs. As you breathe in, your stomach should rise, as you blow out, it should fall.

15. Chair Scoots: start by sitting at the very back of your chair Scoot forward to the front by "walking" your hips forward. Don't lean backwards. Then walk them backwards till you're sitting in your normal position.

16 Ankle Dorsiflexion: sitting with feet flat on the floor, raise your toes up. Hold and then relax.

TRAINEX FILMSTRIP

RANGE OF JOINT MOTION EXERCISES

Definition: ROJM is the extent of movement within a given joint.

General Principles:

1. These exercises retain and rebuild muscle strength. They also prevent stiffness of the joints caused by muscle contractions.
2. Remember to use good body mechanics. Keep the patient relaxed and well-aligned, with her limbs close to her body.
3. Work slowly and smoothly and observing the patient's facial expression for signs of discomfort. Do not exercise the patient past the point of pain.
4. You must have a thorough knowledge of your patient's illness and limitations.
5. Constantly encourage your patient to take a more active part in her exercise program, as independence is one of the major goals of rehabilitation.

Passive Exercise - when the nurse performs an exercise for the patient.

Active Exercise - exercises performed without the help of the nurse or therapist.

Hyperextension of the Cervical Spine or Neck - bending the neck backward.

Flexion of the Cervical Spine or Neck - bending the neck foreward.

Lateral Flexion of the Neck - bending sideways.

Rotation of the Neck - turning the head in a circular motion.

External Rotation of the Shoulder - rotating the arm backward (affects shoulder joint.)

Internal Rotation of the Shoulder - rotating the forearm foreward.

Flexion of the Shoulder Joint - the arm swings foreward and upward.

Extension of the Shoulder Joint - the arm returns to the side of the body.

Hyperextension of the Arm - as it swings backward.

Abduction of the Shoulder Joint - move the arm away from the side of the body.

Adduction of the Shoulder Joint - return the arm to the sice.

Flexion of the elbow - bending of the elbow.

Extension of the Elbow - straightening of the elbow.

Supinate the Hand - rotate the palm upward.

Prorate the Hand - rotate the palm downward.

Ulnar and Radial Deviation - the wrist can deviate toward the little finger side and the thumb side of the hand.

Opposition of the Thumb - placing of the palmer surface of the thumb so that it faces the fingers. Move the thumb in a larger circle twoard each finger and return it to its original position.

Flexion of the Fingers - curl the fingers downward until they form a fist.

Extension of the Fingers - straighten the fingers.

Abduction of the Fingers - spreading the fingers apart.

Adduction of the Fingers - bringing the fingers together.

Flexion of the Knee - bending the knee.

Extension of the Knee - extending the knee.

Abduct the Hip Joint - support the patient's leg at the knee and ankle and bring it it to the side.

Adduct the Hip Joint - reverse the above.

External Rotation of the Hip - roll the hip outward.

Internal Rotation of the Hip - roll the thigh inward.

Dorsiflexion of the Foot - pointing the foot upward.

Planter Flexion of the Foot - pointing the foot downward.

APPENDIX I

Planning An Activity

PURPOSE: What are you trying to accomplish? At the group level? Individual level? Some goals to consider: awareness of self, others, environment: stimulation (physical/mental); interaction: development of skills; carry over into daily life; meeting individual needs: controls, sense of accomplishment, specific motor requirements, etc.

MATERIALS: What materials are needed? What is on hand? Are purchases necessary? Get prior authorization. Can materials be gathered by the members themselves?

I.SKILLS: What adjustments have to be made to fit individual and group needs? (Grading of the activity).

1. Amount of physical exertion required.
2. Degree of emotional threat.
3. Sight requirements
4. Hearing requirements
5. Mental Agility, e.g., concentration, orientation, psycho-motor functions.
6. Mental ability, e.g., reading level.
7. Dexterity/mobility/range of motion/gross and fine motor skills.
8. Motivation/interest (relate to and use life experience of group)
9. Type of materials used: can they be manipulated easily (large enough); note textures, colors, contrasting work surface.

Who in the group already has the required skills? How can these be used to help other members? Who might need individual attention and how can this be accomplished?

STEP BY STEP PREPARATION: Have opportunities been provided for prior discussion and client input? How much of the preparation and planning should be done ahead, how much left to the members themselves? (relate this back to Goals). Introduce the activity using multiple sensory clues (visual, aural, tactile). Present one idea at a time. Consider reality of what can be accomplished in a given work period (relate this back to skills). What are the steps involved? (Break them down). Consider producing a sample of finished product that group can relate to (alternately or concomitantly model along with clients).

TIME: How much time is required? Is this planned for one time period or to extend over many days? Is morning or afternoon most appropriate? Be sure to finish activity!

Staff: Plan staff ratio required, including students, and volunteers.

SAFETY PRECAUTIONS:

1. Securing of materials.
2. Ventilation
3. Handling of sharp equipment
4. Physical limits set for client
5. Amount of supervision required
6. Seating according to physical needs and limitations, e.g., back to light, hard chair, chair with arms.

FOLLOW-UP:

1. Responsibility for cleaning up
2. Storage of unfinished product.
3. Reinforcement of client's effort and accomplishment.

EXIBILITY: What are the conditions on any given day which might require changes in planning, including cancelling the activity altogether?

1. Give priority to immediate confrontation of individual crisis or group conflict
2. General physical/emotional level of the group
3. The weather/transportation

EVALUATION: Purpose and procedure review

1. How did staff function? What adaptations were made?
2. How did client function in task: realistic choices, response to direction, follow through, body function; work habits
3. What is therapeutic value of the activity? To the individual, to the group.

APPENDIX J

GUIDELINES FOR TEACHING OLDER ADULTS

The translation of research findings into suggestions for teaching in the clinical situation is undertaken with a degree of humility. In the first place, research in the area of learning by older people is limited. The great majority of research efforts have been, and still are focused on the learning and teaching of the young. In the second place, the subjects involved in most of the studies are considered "normal", that is, without evidence of the pathological changes experienced by patients in health care settings. Third, direct application of most research findings to practice is rarely possible and may not even be desirable without considering the characteristics of the population being served and the available resources of staff and setting. The cautionary words of Kent seem appropriate "...the world of action cannot always wait upon the world of research, but it is inexcusable to give the impression that we are operating not on the basis of our best guesses given limited evidence but that we are operating on the basis of scientific evidence." Therefore, the guidelines are offered in the spirit of just that --guides. They are not purported to be a set of principles, dictums or a concretized sequence of steps. Such presence would be a disservice to the professional reader and most certainly to the older person he seeks to teach.

Guidelines

The following guidelines take into consideration selected sets of conditions identified by research that influence the learning of aged adults:

1. Select visual aids that minimize the need for visual acuity or precise discrimination.
2. Seek a position in physical relationship to the person so as to maximize the strength and clarity of sensory stimuli.
3. Adjust word/min. rate to a level that makes the auditory inputs clearly perceptible to the person.
4. Determine with the older person the type of aid or media for input that facilitates his learning: e.g., auditory, visual, tactile or some combination.
5. Utilize teaching strategies or materials that permit the person to control the presentation pace of content to be learned.
6. Seek Feedback from the person regarding such things as pace, speech intelligibility, meaningfulness of content.
7. Select a place and time when simultaneous activity in the environment will be minimal in order that competing stimuli will not disrupt the person's learning.
8. Select a time for teaching when the person is not preoccupied with other concerns, e.g., recovery from illness, grieving, or finances.

9. Provide opportunities for recall of new information and practice of performance of tasks preferably within a day's time, or within a week of presentation at most.

10. Relate new learning to the past and present experiences of the person.

11. Integrate new behaviors with established and ongoing behaviors and activities so as to enhance memory.

12. Establish goals for learning that are mutually agreed upon by the older adult and the practitioner.

13. Establish short-term goals that are achievable and related to long-term goals in a meaningful way.

14. Determine what constitutes positive reinforcement for a given individual.

15. Provide opportunities for successful learning, prompt feedback and ample reinforcement for the level of performance achieved by the individual.

16. Encourage the person to participate in decisions related to when, how and what learning is to occur.

17. Encourage the expression and utilization of information brought by the older person to the teaching-learning situation which concerns the individual and situational variables operating in his life and which may relate to his learning.

18. Utilize terminology and examples familiar to the individual.

19. Consider the person's comfort and level of available energy.

20. Capitalize on the older person's (and one's own) reservoir of common sense and sense of humor.

These guides are not mutually exclusive and certainly not all inclusive.

APPENDIX K

Craft Instructions

Arts & Crafts

Manipulative Skill Development For The Older Adult

Purpose:

A basic manipulative skills class for the older adult which concentrates on improvement of motor skills and decision making through utilization of a variety of art media and techniques. Projects are designed to produce items for: personal use, gift giving and selling, emphasizing and utilizing recycled materials.

Objectives:

1. To utilize various materials in a creative and expressive manner.
2. To visually and manually follow instructions in creating objects.
3. To be exposed to many different materials and in the process, originate creative objects.
4. To interact with other participants in a supportive and creative manner.
5. To derive a sense of self-worth and accomplishment through the completion of projects.

CRAFT INSTRUCTIONS

1. BE PATIENT
2. HAVE MODEL MADE.
3. KEEP EVERYTHING SIMPLE
4. KEEP CRAFTS FUNCTIONAL AND/OR CREATIVE.
5. USE LIGHT AND BRIGHT COLORS
6. GIVE SIMPLE INSTRUCTIONS, ONE AT A TIME.
7. BE FLEXIBLE; BE WILLING TO CHANGE INSTRUCTIONS.
8. BE WILLING TO TAKE RESPONSIBILITY IF PROJECT COMES OUT BADLY
9. ACCEPT THEIR SUGGESTIONS
10. KEEP TECHNIQUES FAMILIAR
11. BE ENTHUSIASTIC

APPENDIX L

Facilitating Techniques

1. Active Listening - Feedback (see other sheet)
    a) reflective - clarifying feeling and reason for feeling.
    b) summarizing - verbalizing what you see person doing or saying to help them see what they are doing more objectively.
    c) confrontation - helping people see where behavior and expressed needs or desires do not match so they can take steps to change one or the other.

General Guidelines

1. Do not be too persistent.
2. Do not argue - listen to feelings.
3. Observe non-verbal cues - do not just let them pass.
4. If counselling situation threatens person - begin with general questions then work to more specific.
5. Never ask why.
6. Allow people to be themselves - preserve their dignity.
7. Help them increase their self-determination.
8. Don't force your help on anyone - no one will benefit from counselling unless they are engaged in it.
9. Make sure the person you are talking with understands what you are trying to say- if not- repeat it.
10. Make your communications short - do not put 2 ideas into one sentence. ie. - if you said, "Isn't it a nice day, the grass is blue." The person has to respond to 2 ideas- yes or no the grass is blue.
11. Ask open ended questions- not ones which make a judgement in the question such as - Isn't it a nice day?
12. Keep all committments you make! Make only those you intend to keep.
13. Encourage people to see themselves as a cause of their circumstances rather than the effect (encourage to take responsibility for themselves).

14. Use empathy rather than sympathy.
15. Allow silence when it happens - it is often therapeutic.
16. Cue into the clients feelings rather than words- relate your comments to his/her feelings.

APPENDIX M FEEDBACK

'eedback" is a way of helping another person to consider changing her ehavior. It is communication to a person (or a group) which gives that erson information about how she affects others. As in a guided missile ystem, feedback helps an individual keep her behavior "on target" and hus better achieve her goals.

ome criteria for useful feedback:

1. It is descriptive rather than evaluative. By describing one's own reaction, it leaves the individual free to use it or to use it as she sees fit. By avoiding evaluative language, it reduces the need for the individual to respond defensively.

2. It is specific rather than general. To be told that one is "dominating" is probably not as useful as to be told that "just now when we were deciding the issue you did not listen to what others said and I felt forced to accept your arguments or face attack from you."

3. It takes into account the needs of both the receiver and giver of feedback. Feedback can be destructive when it serves only our own needs of the person on the receiving end.

4. It is directed toward behavior which the receiver can do something about. Frustration is only increased when a person is reminded of some shortcoming over which she has no control.

5. It is solicited rather than imposed. Feedback is most useful after the receiver herself has formulated the kind of question which those observing her can answer.

6. It is well-timed. In general, feedback is most useful at the earliest opportunity after the given behavior focussing, of course, on the person's readiness to hear it, support available from others, etc.

7. It is checked to insure clear communication. One way of doing this is to have the receiver try to rephrase the feedback she has received to see if it corresponds to what the sender had in mind.

8. Both the giver and the receiver check with others in the group the accuracy of the feedback. Is this one person's impression or an impression shared by others.

Feedback, then, is a way of giving help. It is a corrective mechanism for the individual who wants to learn how well her behavior matches her intentions are and it is a means for establishing one's identity for answering WHO AM I?

Adapted from University Associates material

CND 12/76

HOW TO TALK WITH PARTICIPANTS ABOUT SENSITIVE SUBJECTS

I. Talking About Death

A. General Issues

1. Expect Resistance - especially if you have never talked about it (for example - your group focused on happy topics)

2. Start Slowly - bring up the subject as it comes up - for example if someone in the program dies, or a relative dies. - This will eventually become a natural part of the group - but it takes time.

3. Death is a part of life - even more so with the elderly. Even if you do not talk about it - it will affect the group. It is better to bring out sad and difficult topics - participants can then further benefit from other parts of the program.

4. Help Participants to help each other - Don't try to "Solve" each persons grief yourself - let the participants share coping mechanisms with each other - you can help guide the discussion and encourage others to share.

B. Some Specific Techniques

1. Values Clarification Exercise:
Have participants discuss this question - each choose one and say why. For example "Which of these would be more difficult for you to accept?"
- the death of a parent
- the death of a spouse
- your own death
make sure to stress there are no right or wrong answers - just each individuals feelings.

2. Memorial Board & Book
After a participant dies - put their picture on a board - have participants write memories of person - have album with pictures and memories to keep them.

3. If someone expresses emotions: for example crying, anger, etc. Do not stop them if others in the group start to feel uncomfortable - help them to share with the person expressing grief and to share coping mechanisms as above.

APPENDIX O BEHAVIOUR RATINGS SCALE

Please indicate how well the following items describe ______________________

1. hardly at all 2. fairly well 3. well 4. very well 5. completely

1. Does not take part in family conversations	1	2	3	4	5
2. Does not read newspapers, magazines, etc.	1	2	3	4	5
3. Sits around doing nothing	1	2	3	4	5
4. Does not show an interest in news about friends and relatives	1	2	3	4	5
5. Does not start and maintain a sensible conversation	1	2	3	4	5
6. Does not respond sensibly when spoken to	1	2	3	4	5
7. Does not understand what is said to him/her	1	2	3	4	5
8. Does not watch and follow television	1	2	3	4	5
9. Does not keep him/herself busy doing useful things	1	2	3	4	5
10. Fails to recognize familiar people	1	2	3	4	5
11. Gets mixed up about where he/she is	1	2	3	4	5
12. Gets mixed up about the day, year, etc.	1	2	3	4	5
13. Has to be prevented from wandering outside the home	1	2	3	4	5
14. Hoards useless things	1	2	3	4	5
15. Talks nonsense	1	2	3	4	5
16. Appears restless and agitated	1	2	3	4	5
17. Gets lost in the house	1	2	3	4	5
18. Wanders outside the house at night	1	2	3	4	5
19, Wanders outside the house and gets lost	1	2	3	4	5
20. Endangers him/herself	1	2	3	4	5
21. Paces up and down wringing his/her hands	1	2	3	4	5
22. Wanders off the subject	1	2	3	4	5
23. Talks aloud to him/herself	1	2	3	4	5
24. Seems lost in a world of his/her own	1	2	3	4	5
25. Mood changes for no apparent reason	1	2	3	4	5
26. Becomes irritable and easily upset	1	2	3	4	5
27. Goes on and on about certain things	1	2	3	4	5
28. Accuses people of things	1	2	3	4	5
29. Becomes angry and threatening	1	2	3	4	5
30. Appears unhappy and depressed	1	2	3	4	5
31. Talks all the time	1	2	3	4	5
32. Cries for no obvious reason	1	2	3	4	5
33. Looks frightened and anxious	1	2	3	4	5
34. Gets up unusually early in the morning	1	2	3	4	5

APPENDIX P

BURDEN INTERVIEW

NAME ______________________

Please indicate how much discomfort you feel by circling the appropriate number between 1 and 5 for each statement below.

	not at all 1	a little bit 2	somewhat 3	quite a bit 4	extremely 5
1. I feel resentful of other relative's who could but who do not do things for my relative.	1	2	3	4	5
2. I feel that my relative makes requests which I perceive to be over and above what s/he needs.	1	2	3	4	5
3. Because of my involvement with my relative, I don't have enough time for myself.	1	2	3	4	5
4. I feel stressed between trying to give to my relative as well as to other family responsibilities, job, etc.	1	2	3	4	5
5. I feel embarrassed over my relative's behavior.	1	2	3	4	5
6. I feel guilty about my interactions with my relative.	1	2	3	4	5
7. I feel that I don't do as much for my relative as I could or should.	1	2	3	4	5
8. I feel angry about my interactions with my relative	1	2	3	4	5
9. I feel that in the past, I haven't done as much for my relative as I could have or should have.	1	2	3	4	5
10. I feel nervous or depressed about my interactions with my relative.	1	2	3	4	5
11. I feel that my relative currently affects my relationships with other family members and friends in a negative way.	1	2	3	4	5
12. I feel resentful about my interactions with my relative	1	2	3	4	5
13. I am afraid of what the future holds for my relative.	1	2	3	4	5
14. I feel pleased about my interactions with my relative.	1	2	3	4	5
. It's painful to watch my relative age.	1	2	3	4	5

Burden Interview, cont.

16. I feel useful in my interactions with my relative	1	2	3	4	5
17. I feel my relative is dependent.	1	2	3	4	5
18. I feel strained in my interactions with my relative.	1	2	3	4	5
19. I feel that my health has suffered because of my involvement with my relative.	1	2	3	4	5
20. I feel that I am contributing to the well-being of my relative.	1	2	3	4	5
21. I feel that the present situation with my relative doesn't allow me as much privacy as I'd like.	1	2	3	4	5
22. I feel that my social life has suffered because of my involvement with my relative.	1	2	3	4	5
23. I with that my relative and I had a better relationship.	1	2	3	4	5
24. I feel that my relative doesn't appreciate what I do for him/her as much as I would like.	1	2	3	4	5
25. I feel uncomfortable when I have friends over.	1	2	3	4	5
26. I feel that my relative tries to manipulate me.	1	2	3	4	5
27. I feel that my relative seems to expect me to take care of him/her as if I were the only one s/he could depend on.	1	2	3	4	5
28. I feel that I don't have enough money to support my relative in addition to the rest of our expenses.	1	2	3	4	5
29. I feel that I would like to be able to provide more money to support my relative than I am able to now.	1	2	3	4	5

(Relatives of the Impaired Elderly: Correlates of Feelings of Burden, Steven H. Zarit, Ph.D., Karen E. Reever, MPA/MSG Julie Bach-Peterson, MSG, Andrus Gerontology Center, Univ. of Southern California, Los Angeles, CA.)

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APPENDIX Q
SECOND LEVEL OBSERVATION

SELF CARE: Describe patient as he enters workshop indicating dress, grooming and general appearance.

TASK BEHAVIOR: (Observation, not inferences.)

1. Decision Making: Summarize the decision-making behavior considering the following questions:
    a. How does your patient choose and initiate a project?
    b. Does he start one independently?
    c. Does he ask for suggestions? From whom?
    d. Does he wait until the O.T. asks him what he wants to do and/or assigns him a task?

2. Learning Style: Summarize the patient's learning style considering the following questions:
    a. What are his methods of learning?
        1. Demonstration
        2. Written materials
        3. Imitation of others
        4. Trial and error
    b. What behaviors indicated this was his learning style?
    c. Did the patient have access to using more than one of these approaches to learning?

3. Problem Solving: Summarize the patient's problem solving behavior considering the following questions:
    a. Can your patient identify if he has a problem?
    b. Can he identify what it is?
    c. How does he attempt to solve it?
        1. What does he do on his own?
        2. How does he utilize resources? (People and/or learning materials?)
    d. How does he handle constructive criticism or suggestions?

4. Goal Directed Behavior: Summarize patient's goal directed behavior considering the following questions:
    a. How long can he attend to a project?
    b. Can he set his own goal?
    c. Can he identify and implement steps necessary to complete a goal?
    d. Is he able or can he delay gratification until task completion?

5. Use of Resources: Summarize the patient's responses to supervision considering the following questions?
    a. When he has a problem to whom does he turn for assistance?
    b. When he gets suggestions does he make use of them? Does he act defensively?

6. Social Interactions: Summarize the patient's social interactions considering the following questions:

   a. Does he seek interaction with staff or other patients?
   b. Do others seek him out?
   c. What is the content and quality of interaction?

7. Skill Performance: Summarize the patient's level of performance considering the following questions:

   a. Can he recognize the quality of his work?
   b. Does he apply proper techniques, exercise care, and interest in the project?

ASSESSMENT: Based on the above information identify the patient's strengths and problem areas in basic functioning.

APPENDIX R

STAFF EVALUATION

RATING SCALE
[illegible]
[illegible]
3 = [illegible]
4 = [illegible]

I. Leadership Skills

A. Professional attitude

1. Is aware of social environment and social issues; understands implications for practice

2. Recognizes and appreciates uniqueness including [illegible]

3. Understands and accepts role responsibilities

B. Demonstration of practice

1. Is aware of self and implications of self style

2. Insures client participation throughout [illegible] program process.

3. Is able to modify assessments, goals and [illegible]

4. Knows and uses resources

5. Motivates other staff in performance of [illegible]

[illegible]

[illegible]

II. Communication:

A. Professional

1. Communicates effectively both verbally [illegible]

2. Facilitates active involvement of indiv[illegible] groups among participants

3. Conducts and/or participates in staff [illegible]

B. Communication-Overall (Development of [illegible]

1. Constructively manages conflict and [illegible]

2. Uses supervision for professional dev[illegible] opportunity for learning.

3. Broadens and deepens own profession[illegible]

4. Able to advocate and assert for [illegible] client needs.

III. Follow-Through

A. Work Management (task)

1. Manages multiple work responsibilities effectively

2. Organizes tasks and levels of involve[illegible] efficiency

3. Takes initiation in the performance and completion duties

1. Cooperates with co-workers and supervisors

2. Maintains awareness of overall [illegible]

3. Willing to share in unpleasant tasks

4. Exhibits responsible behavior in attendance

5. Exhibits responsible behavior in punctuality

IV. Additional Feedback Evaluation and Staff

A. Recommendation:

B. Comments:

C. Points of Improvement

D. Plans for Employee Development

Employee Signature

Executive Director

d. A current list with mailing addresses of the Executive Committee or Officers of the Board, if any;

e. If staff have been engaged, a record of satisfactory medical examination of each staff member who will come into contact with the participants and those who will be engaged in handling and preparation of food, (see IV D. 10.);

f. Samples of all forms used such as, but not limited to application forms, agreement forms, etc.;

g. Certificate of Occupancy: The applicant shall provide, where applicable, a copy of a certificate of occupancy from the local building official for each building to be used, as evidence of compliance with the Uniform Statewide Building Code;

h. A sketch of floor plan of the entire building. Exact measurements including floor area shall be submitted.

- Fee: there is no fee for a State license.
- Study of the Application: Following receipt of the application and material requested in G. 2., a representative of the Department will make a study of the proposed services and facilities of the applicant. The Department will request an inspection and report as to the sanitary conditions from the local health department. Where applicable, the Department will request inspections and report as to fire safety from State and local fire officials.

4. Buildings and Equipment

The following provisions are worthy of reference:

- Buildings shall meet State and/or local building codes.
- The facility shall be properly maintained. Both exterior and interior shall be repaired when and where needed and

shall be free from safety hazards. All areas shall be clean. Each occupied room shall have smooth floors and/or carpeting, walls, and ceilings shall be so finished as to enable satisfactory cleaning.

- A licensed day care facility shall provide a minimum allowance of twenty square feet of indoor activity/ recreation space per participant.

- All doors and windows shall open and close readily and effectively. Screen doors shall open outward. Outer openings that are regularly used for ventilation shall be effectively screened and open and close readily.

- Before construction has started or contracts are awarded for any new construction, remodeling, or alterations, plans shall be submitted to the Department, the local health department, the State Fire Marshall's office, where applicable, and to the local building official, where applicable, for review and recommendations.

- Rooms extending below ground level shall not be used for participants unless they are dry, well-ventilated and have adequate window space for illumination by daylight.

- Facilities shall be available for those participants who wish to rest regularly or occasionally, or for emergencies. There shall be provision for privacy. Beds or cots shall not be placed in corridors, kitchens, basements or attics.

- Toilet facilities, including handwashing facilities, shall be provided and shall have a minimum of a self-closing door, if they open into a room used for storage, preparation or service of food.

- Where there are men and women, there shall be separate toilet facilities.

- An ample supply of hot and cold water shall be available at all times. Hot water shall be at least 110° F. and thermostatically controlled.
- Grab bars shall be installed by all toilets.
- Heat shall be supplied from a central heating plant or an approved electrical heating system. All rooms used by participants shall be supplied with heat so that a temperature suitable for aged, infirm or disabled persons is maintained.
- All areas shall be well lighted for safety and activities. Recreation areas shall have 50 footcandles of light. All other areas shall have 30 footcandles of light as registered on a light meter.
- Artificial lighting shall be by electricity. Lighting shall comply with local fire and electrical wiring regulations. Approved emergency lighting facilities such as flashlights or battery lanterns shall be provided and available at all times. Outside lighting shall be provided for protection against injuries and intruders.
- Handrails shall be provided on all inside and outside stairs, ramps and elevators. Safeguards shall be provided for hazardous windows, doors, open porches, changes in floor level, and similar accident hazards and shall be acceptable to existing fire and/or building codes. Danger areas on the property outside the building shall also be safeguarded.
- Elevators where used, shall be kept in good running condition and shall be inspected in accordance with State and/or local statutory requirements. A copy of the inspection report shall be made available to the Commissioner's representative upon request.

- Where nonambulatory participants are cared for, doorways and ramps shall permit passage of wheelchairs. Ramp(s) shall be provided at the ground floor.
- A sufficient number of trays, dishes, and flatware shall be provided so that each participant has the necessary utensils and so that food is served attractively.
- Trays, dishes and flatware shall be easily cleanable, safe and shall not have chips, cracks and/or dents.
- Disposable dishes and utensils, if used, shall be used once and discarded, and shall be sturdy enough to prevent them from being a safety hazard.

5. Fire Protection

- A day care center shall meet the Virginia Fire Safety Regulations and/or the Uniform Statewide Building Code where they apply as well as any local applicable fire regulations.
- All facilities shall be free from fire hazards as determined through inspections and reported on a form provided by the Department.
- A detailed fire plan shall be worked out for each facility. Wherever possible, this plan shall be drawn up with the advice of the local fire department or fire prevention bureau. This shall be posted in a conspicuous place. The director and all employees shall be fully informed of the fire plan for the facility, including their duties, location, and operation of fire extinguishers, fire alarm boxes, and telephone procedure in calling the fire department. Fire drills for the staff and those participants able to participate shall be held at least quarterly. The drills shall be planned and announced in advance. All participants shall know what procedure will take place

for him/her in case of fire. At the time of orientation for both staff and participants, the details of the fire plan shall be discussed including where the written fire plan is posted. This shall be reviewed at the time of the quarterly fire drills. A permanent record of fire drills held shall be kept in the facility for two years.

- Nonambulant participants shall not be placed in rooms on any floor above the ground level, without approval of the Department.

6. Sanitation and Preventive Health Measures

- The entire premises shall be kept neat, clean, and free from all accumulations of dirt and rubbish and be well ventilated and free from foul, stale, and musty odors. In centers with ten (10) or more participants, Title 35, Chapter 3, Sections 32-35 through 35.42.1, Code of Virginia, and all regulations adopted thereunder shall apply to the provisions of food service facilities and maintenance thereof.

- Adequate provisions for the collecting and legal disposal of garbage, ashes, and waste material shall be provided. Covered, vermin-proof, metal watertight containers shall be provided for garbage, ashes, and waste material. Containers shall be emptied and cleaned at least once a week.

- Premises shall be kept free of flies, roaches, rats and other vermin.

- Infectious waste material shall be legally and sanitarily disposed of.

- Storage space separate from foods shall be provided for cleaning supplies.

- All drinking and eating utensils shall be air dried if a dishwasher is not used. They shall not be dried with a towel.

- The center shall make provisions for the proper washing of bed, bath, table and kitchen linens and other washable goods either on or off the premises. If this is to be done on the premises, it shall not be done in a food preparation, storage, or service area. Soiled bed, bath, kitchen and table linens shall be laundered according to accepted methods of the Virginia Department of Health.

- If cloth napkins are used, they shall be used only once and laundered.

- Tablecloths shall be changed when soiled.

- Fresh kitchen linens shall be provided daily beginning with the first meal of the day.

- There shall be no smoking permitted by personnel while engaged in food preparation and service.

7. Health Care and Supervision

- The director and employees shall not abuse or punish any participant by any method including but not limited to physical force, confinement, withholding food, exclusion from activities, or speaking abusively.

- Special supervision and assistance shall be given to those persons who are unable to keep themselves neat and clean.

- Whenever a participant suffers serious illness or accident, the attending physician, the next of kin or other designated person and/or cooperating agency(ies) shall be notified of such condition immediately. All illnesses or accidents that occur at the center shall be regularly entered into the participant's record, including what was done by staff and/or where the person was sent for treatment.

- No medical or dietary program or system of medication shall be started or continued without a written order of a licensed medical doctor.

- The medicine cabinet or closet shall be conveniently located, not in the kitchen, and adequately illuminated with 100 footcandles measured on a light meter. All medications shall be securely locked and accessible only to a responsible person in charge. A record shall be kept of all drugs taken.

- A responsible person shall be designated to distribute drugs from the locked cabinet to the proper participant named on the prescription label. For purposes of this requirement, a responsible person is defined as one who is not tempted to use the drugs personally and who is capable of reading the prescription label and distributing drugs to the proper person.

- Only those persons authorized by the State law to administer or dispense controlled drugs shall be permitted to do so. This may include licensed doctors, nurses, physicians' assistants, or other individuals who have met the State requirements to perform these functions. NOTE: An authorized agent of the physician may administer drugs in accordance with such physician's instructions pertaining to dosage, frequency and manner of administration when the drugs administered would be normally self-administered by a participant, as provided by Code of Virginia, Section 54-524.65, as amended.

- If a participant becomes disturbed and unmanageable, the attending physician and the family shall be notified promptly. Methods of physical restraint shall not be used except in an emergency and/or under the direction of the participant's physician or an available physician. A written report shall be filed with the director of the center by any staff member involved in a physical restraint of a participant with a copy of the report being filed in the participant's record. If such a participant does not respond promptly to the treatment prescribed by the attending physician, arrangements shall be made for his removal from the center.

8. Food Service and Nutrition

- Each facility shall have a dining area adequate to serve all participants either all at one time or in shifts.

- Catering service, if used shall be approved by State and/or local health department and catered food shall meet dietary requirements set forth in these standards.

- Lunch shall be as evenly spaced as possible between breakfast and supper, never closer than four (4) hours.

- Food and nutritional needs of the participants shall meet dietary allowances as prescribed in printed form by a recognized authority such as but not limited to The Food and Nutritional Board of the Nutritional Research Council, The United States Department of Health, Education, and Welfare, Public Health Service, The Virginia Department of Health, The Virginia Polytechnic Institute Extension, etc., and/or the attending physician's orders.

- If a participant has not had breakfast before coming to the center, breakfast or a snack shall be served soon after his/her arrival.

- A menu for snacks and meals shall be planned for at least two weeks at a time and posted. 1) Any changes shall be noted. 2) A record of menus actually served shall be retained for six months.

- Religious dietary laws (or practices) of the director shall not be imposed upon participants unless mutually agreed upon in contract with director and particpant. The participants' religious dietary practices shall be recognized and respected by the director.

- There shall be a supply of staple foods on hand to meet emergencies.

9. Activities

- The director shall be responsible for making available programs within the facility that will be appropriate to the needs, interest and abilities of the participants.

- Indoor Facilities (Living or Recreational Room): Twenty (20) square feet per participant of living and/or recreational room(s) shall be provided for the participants of the facility for use for visits with each other, with relatives and friends, for small group activities and for larger social events. Included in this area shall be books, magazines, newspapers and games. The dining room may be used for recreational purposes.

- Outdoor Facilities: Each facility shall provide for outdoor activities. Such an outdoor area shall be reasonably secluded from traffic noise, and include a safe walk area, and be available to all participants. If a facility has no available space for outdoor activities, staff or volunteers shall be available to escort participants on walks, transport them to nearby parks, etc. No participants shall be confined to indoor activity due to lack of adequate staff or outdoor facilities.

- Activity Program: Activities shall include such things as, but not limited to, the following: arts and crafts for both men and women, music, religious programs, celebrations (for birthdays, holidays, and special events), picnics, library programs, informal social activity, sports activities, gardening, games, trips, card clubs, fishing, discussion groups, etc.

- Volunteers

  a. Where volunteers are used in the facility, they shall: be used to enrich the program; have qualifications appropriate to the services they render; and be subject to the same regulations on confidentiality as are staff members.

  b. The director or an employed staff member shall be in charge of the volunteer program including the planned orientation to the center.

  c. If volunteers are used as regular staff (i.e., assuming staff duties on a scheduled basis), the licensee or director shall enter into a written agreement(s) with the volunteer(s) specifying duties, hours, and any other special considerations such as meals, transportation, etc. The volunteer(s) shall meet all health and personnel requirements for regular staff if so utilized.

  d. To limit disruption to the program of the center and disappointment of participants, staff members in charge of volunteers shall determine during the early stage of involvement whether the volunteer demonstrates dependability for a particular assignemnt.

  e. Turnover of volunteers shall be kept to a minimum.

  f. The center shall 1) establish requirements for the selection of volunteers; 2) have an agreement between itself and the individual volunteer, agreeing on the latter's job assignment; and 3) clearly differentiate the volunteer's responsibility from staff members.

- Use of Community Resources: Each director shall avail himself/herself of as many of the various community resources and services as possible to provide a well-rounded activity program for the participants who are willing and capable of participating in them.

All of the standards pursuant to the sections on "General Regulations," "Records," and "Management and Personnel" are in accordance with the policies and procedures outlined in this proposal.

APPENDIX T

Letter to Zoning Administrator

Mr. Phillip Yates
Zoning Administrator
Fairfax County
10555 Main Street
Fairfax, VA 22050

Dear Mr. Yates:

The Alzheimer's Disease and Related Disorders Association of Northern Virginia is interested in exploring the feasibility of developing an adult day care center in Fairfax County. A summary of the proposed program is enclosed for your information.

Central to our determination are the time, costs, and actions required of us by the County zoning requirements. We also understand that the appropriate zoning category is significant to the process requirements.

Can you provide us with information pursuant to these concerns?

Your guidance and suggestions on how we might most efficiently pursue our interests would be most appreciated.

Sincerely,

Lin Noyes
President

Enclosure

APPENDIX B

Family Respite Center, Inc
2036 Westmorland Street
Falls Church, Virginia 22043

ANNUAL REPORT
June 30, 1984 - June 30, 1985

This year, June 30, 1984 through June 30, 1985, has been an exciting one, filled with challenges and rewards. We have all worked hard to reach our goal of opening a day care center for people suffering from dementing illnesses.

This first annual report summarizes our year's activities and highlights events which have significance for future planning.

We are most grateful to all the individuals and organizations who have helped us during this first year. Their number has been significant and their offerings in talent and gifts have made our accomplishments possible.

Summary of Activities

Several years ago, a family support group of the Alzheimer's organization in Northern Virginia expressed its desire to start a day care center for victims of Alzheimer's-type diseases. In May 1983 a planning committee was named by the Chapter and in July 1983, the first donations from Knights of Columbus, Mount Vernon Council were received. This first donation pushed our dream into the real world. Finding a site for the Center was difficult but finally in June 1984 a home for the Center was found. Reverend John Keating, Bishop of Arlington, offered space in Paul VI High School for one year so that we could open the Center and demonstrate our effectiveness to the community.

On July 13, 1984 a non-profit corporation in the State of Virginia was formed and named the Family Respite Center, Inc.

After several zoning delays we opened our doors on September 27, 1984. We began part time serving three participants two days a week. Gradually our enrollment increased and in April 1985 we opened full time: Monday through Friday, 7:30 am to 5:30 pm.

In June 1985 we averaged 8.1 participants per day having served 34 families during our first partial year of service.

Our efforts to relocate the Center at the end of our year's lease at Paul VI High School culmininated in the move to our new home in the Chesterbrook Presbyterian Church. We are grateful to this congregation for housing us and look forward to a long stay at this site.

The staff has been small, steady, dedicated and flexible, adapting to new care techniques day-by-day. Two of our three staff members have been with the Center since it opened and another part time person was hired after having served as a volunteer. We have had a few employees who stayed for a short period of time. One of them is a graduate student in nursing who will be working with us during the summer.

"Related" Activities

The Center not only provides day care but also strives to educate and support others involved in caring for the memory-impaired. In May a workshop titled "Caring for Alzheimer's Patients" was held for nurses aides, respite companions and others who provide "hands-on" care. It was attended by 26 people who gave the program a "better than average" rating. We have planned a major conference for September 1985, "Right to Respite, Right to Care" for health professionals.

In addition to this formal program, 31 talks were given this year to community groups and university students to teach them about Alzheimer's and the Family Respite Center.

We had 47 new visitors (recorded) come to our Center during the year to learn about Alzheimer's or observe the work of our Center. We also had eight college students come to the Center as part of their educational process. Finally, we were visited seven times by newspapers, television or radio reporters interested in spreading the word about Alzheimer's Disease. We were noted in USA Today, The Washington Post and The Journal. We were interviewed for local TV, cable and public broadcasting programs.

Hopefully, this media exposure will lead the general public to a better understanding of Alzheimer's Disease and greater awareness of the work of our Center.

ADMISSIONS AND DISCHARGES

Admissions

Between September 27, 1984 and June 30, 1985 34 people were admitted to the Center and came for at least one day of service. Fifteen of these people are still enrolled in the program. Of those admissions 23 were women, 11 were men. Their ages ranged from 48 to 93 with an average age of 73. Eleven came from other day care centers/senior centers, two were referred by social workers, four were referred by doctors and the remaining 17 have been "self" referrals, either through the Alzheimer's organization or media notices. The relationships of the program participants to the caregivers were as follows: 12 were parents, 18 were spouses and four were related in other ways.

The average length of stay for the initial period was 3.69 months, with an average attendance of 2.8 days per week. Although the majority of those attending are ambulatory, two came in wheelchairs and four required assistance of walkers, canes or another person.

Table 1 represents the growth of the Center, month by month and gives the total number of participant days. The last column shows our projection which was made in January 1984. This projection represents the average number of clients per day we expected to serve in order to meet our business "break even" point.

Discharges

There have been 19 discharges for the following reasons:

- Two died suddenly
- Three died after a short illness (less than three months)
- Three "self" discharged by Center relocation
- Three went to nursing homes
- Six returned to care of their families
- One moved to another area
- One went to a home for adults

Only one of the discharges was at the request of the Center; the rest were initiated by families or an event (e.g., family moving). Distance to and from Center and difficulty getting participants to the Center were among the reasons that families withdrew their loved ones from the program.

Scholarships

It is the intention of the Board of Directors that no one be turned away from the Center for lack of funds. This year seven people came to the Center paying less than $22.80 per day. Six received partial reductions in fees and one came for free.

The following shows the amount of money earmarked as scholarship (that is, the collective reduction in client fees for the month due to "scholarship agreement").

September	$ 45.60	February	$250.00
October	239.40	March	433.20
November	296.40	April	476.90
December	198.80	May	531.20
January	22.80	June	225.60

Total for Year: $2,719.90

Looking Ahead

Throughout the next year we will endeavor to bring this Center to a capacity of 20 participants per day and cover program costs through client fees and scholarship donations. We will be investigating staff benefits including health and dental policies. We will be looking to expand our program to include research opportunities and more formal educational programs for families and other caregivers of Alzheimer's patients.

Additionally, we will be looking at ways to expand our services to include short term and long term respite care as well as day care.

TABLE 1

Client Service Record for Year Ending June 30, 1985

	Days Opened	Clients Served	Participant Days	# of Clients Per Day	Projected # Clients/Day
July 84	0	0	0		0
August 84	0	0	0		0
September 84	5	3	15	3.0	3.1
October 84	12	8	32	2.7	2.6
November 84	16	10	61	3.8	3.3
December 84	12	14	55	4.6	4.2
January 85	18	14	69	3.8	4.8
February 85	15	18	96	6.4	6.2
March 85	16	19	117.5	7.3	8.0
April 85	18	21	128	7.1	8.2
May 85	23	23	167	7.6	10.5
June 85	15	27	122	8.1	13.4
Totals	150	34	862.5	5.38 (avg)	6.43 (avg)

Notes:

Days Opened: The number of days during the month for which the Center was opened to participants.

Clients Served: The actual number of participants we served during the month.

Participant Days: Basic unit of measuring service; one client came for one day of service.

Average Number of Clients Per Day: Participant days divided by days opened for a month.

Projected Average Number of Clients Per Day: This number was used as a basis for budgeting and represents a six percent growth rate per week.

Table 2 is a presentation of the cost of the program month by month. It is clear that as participant days increase, cost per day is decreased. When enrollment reaches 20 clients per day, cost should equal $22.66 per day.

TABLE 2

Cost of Program

Month	Participant Days	Total Expenses	Cost/Day
June	0	0	0
July	0	58.03	0
August	0	215.20	0
September	15	763.87	50.93
October	32	4,937.19	154.28
November	61	4,674.35	76.63
December	55	3,804.70	69.18
January	69	5,044.04	73.11
February	96	1,820.82	18.97
March	117.5	9,137.73*	77.76
April	128	2,838.86	22.18
May	167	3,874.18	23.20
June	122	5,858.69	48.02
Total for Year	862.5	$44,021.80	61.43 (Avg cost/day)
Projected	400	$ 9,065.04	22.66

* This month is extrordinarily high because of payday scheduling irregularities and includes legal fees for start-up.

DATE 11/12/85

FAMILY RESPITE CENTER INC
GENERAL LEDGER
INCOME STATEMENT
FOR PERIOD ENDED 06/30/85

	THIS YEAR				BUDGET	
INCOME	THIS MONTH	RATIO	12 MONTHS	RATIO	THIS MONTH	12 MONTHS
E STATEMENT						
E						
CLIENT FEES	2,716.60	189.0	14,107.12	14.5	6,710.75-	20,920.03-
GRANTS & LARGE DONATIONS	5,000.00-	347.9-	64,900.00	66.5	0.00	0.00
SCHOLARSHIP DONATIONS	0.00	0.0	5,025.00	5.2	0.00	0.00
MEMORIAL DONATIONS	350.00	24.4	598.00	0.6	0.00	0.00
GENERAL DONATIONS	1,889.31	131.4	5,891.97	6.0	0.00	0.00
FUNDRAISING RECEIPTS	3,318.62-	230.9-	1,597.19	1.6	0.00	0.00
DONATED CAPITAL	4,800.00	334.0	4,800.00	4.9	0.00	0.00
OTHER INCOME	0.00	0.0	404.00	0.4	0.00	0.00
HONORARIUM INCOME	0.00	0.0	200.00	0.2	0.00	0.00
TOTAL INCOME	1,437.29	100.0	97,523.28	100.0	6,710.75-	20,920.03-
SES						
CONSULTING FEES	0.00	0.0	5,748.99	5.9	0.00	0.00
GROSS SALARY	3,472.18	241.6	22,649.87	23.2	5,040.48	35,674.73
FEDERAL TAXES WITHHELD	748.31-	52.1-	0.00	0.0	0.00	0.00
SOCIAL SECURITY WITHHELD	141.39	9.8	0.00	0.0	0.00	0.00
VIRGINIA TAXES WITHHELD	81.21	5.7	0.00	0.0	0.00	0.00
NET SALARY	243.77	17.0	0.00	0.0	0.00	0.00
INSERVICE	0.00	0.0	82.21	0.1	0.00	0.00
OFFICE EXPENSES	147.38	10.3	431.22	0.4	20.00	190.00
PRINTING	0.00	0.0	170.56	0.2	0.00	0.00
POSTAGE	0.00	0.0	225.06	0.2	0.00	0.00
PUBLICITY	0.00	0.0	330.00	0.3	50.00	475.00
LEGAL	0.00	0.0	1,734.53	1.8	83.00	788.50
ACCOUNTING	0.00	0.0	75.00	0.1	42.00	399.00
TELEPHONE	61.25	4.3	713.19	0.7	60.00	570.00
MEAL PREPARATION	0.00	0.0	0.00	0.0	536.86	2,232.05
UTILITIES	0.00	0.0	0.00	0.0	200.00	200.00
INSURANCE	0.00	0.0	1,654.36	1.7	252.00	2,394.00
RENT	500.00	34.8	3,000.00	3.1	1,250.00	3,750.00
CENTER CONSUMABLES	26.41	1.8	1,377.46	1.4	0.00	0.00
PARTICIPANT CONSUMABLES	0.00	0.0	157.89	0.2	67.10	449.03
DEPRECIATION EXPENSE	26.01	1.8	26.01	0.0	0.00	0.00
FOOD	339.68	23.6	1,097.46	1.1	0.00	0.00
FEES	0.00	0.0	84.00	0.1	0.00	0.00
PAYROLL TAX EXPENSE	791.34	55.1	1,206.00	1.2	0.00	0.00
MOVING EXPENSE	2,031.50	141.3	2,031.50	2.1	0.00	0.00
START UP EXPENSES	261.00-	18.2-	1,226.49	1.3	0.00	0.00
TOTAL EXPENSE	6,852.81	476.8	44,021.80	45.1	7,601.44	47,122.31
GROSS INCOME	5,415.52-	376.8-	53,501.48	54.9	14,312.19-	68,042.34-

AMILY RESPITE CENTER, INC.
STATEMENT OF REVENUE, EXPENSES, AND FUND BALANCES-CASH BASIS
FROM JULY 13, 1985 (DATE OF INCEPTION) TO JUNE 30, 1985

REVENUE	
Donations	
Grants and Large Donations	$ 64,900
Scholarship Donations	5,025
Memorial Donations	598
Property Donations	4,800
General Donations	5,892
TOTAL DONATIONS	81,215
Other Revenue	
Client Fees	14,107
Fundraising -Net of Expenses of $ 572	1,597
Other Income	604
TOTAL OTHER REVENUE	16,308
TOTAL REVENUE	97,523
EXPENSES	
Program Services	
Consummables	1,535
Consulting fees	5,749
Depreciation	26
Food	1,097
Inservices	82
Insurance	1,654
Moving Expenses	2,032
Rent	2,850
Printing, Postage and Publicity	669
Salaries	12,133
Start-up expenses	981
Taxes-Payroll	646
Telephone	643
TOTAL PROGRAM SERVICES EXPENSE	30,097
Supporting Services	
General Administration	
Legal and Accounting	1,810
Office Expense	793
Salaries	7,508
Start-Up Expenses	245
Taxes-Payroll	400
TOTAL GENERAL ADMINISTRATION EXPENSES	10,756
Fundraising	3,169
TOTAL SUPPORTING SERVICES EXPENSES	13,925
TOTAL EXPENSES	44,022
EXCESS OF REVENUE OVER EXPENSES	53,501
BEGINNING FUND BALANCES	0
ENDING FUND BALANCES	$ 53,501

UPDATE - JUNE TO OCTOBER 1985

The move to Chesterbrook Presbyterian Church in June 1985 has caused some changes in our planning and budgeting. According to our original plan, the Center would reach capacity in September 1985 after one year of operation. Our growth has continued and in October we averaged 12.8 participants per day (see Table 3), but we have not reached capacity, consequently we have not reached our "break-even" point where client revenues will cover operating expenses. Break-even occurs when 20 clients come and pay $22.80 per day. We have reforecast and now expect to reach capacity in June 1986.

The cost per day figures are shown on Table 4 and illustrate that as our growth continues our expenses have decreased to $30 to $35 per day. The analysis of average gross income between July and October (Table 5) shows that our monthly expenses average $3,000 a month below our income. This money is drawn from savings and currently (as of November 30, 1985) there is a balance of $31,139.44 in this account.

We will continue our efforts to increase enrollment at the Center and continue our efforts to educate others in the care of Alzheimer's disease victims.

TABLE 3

Client Service Record

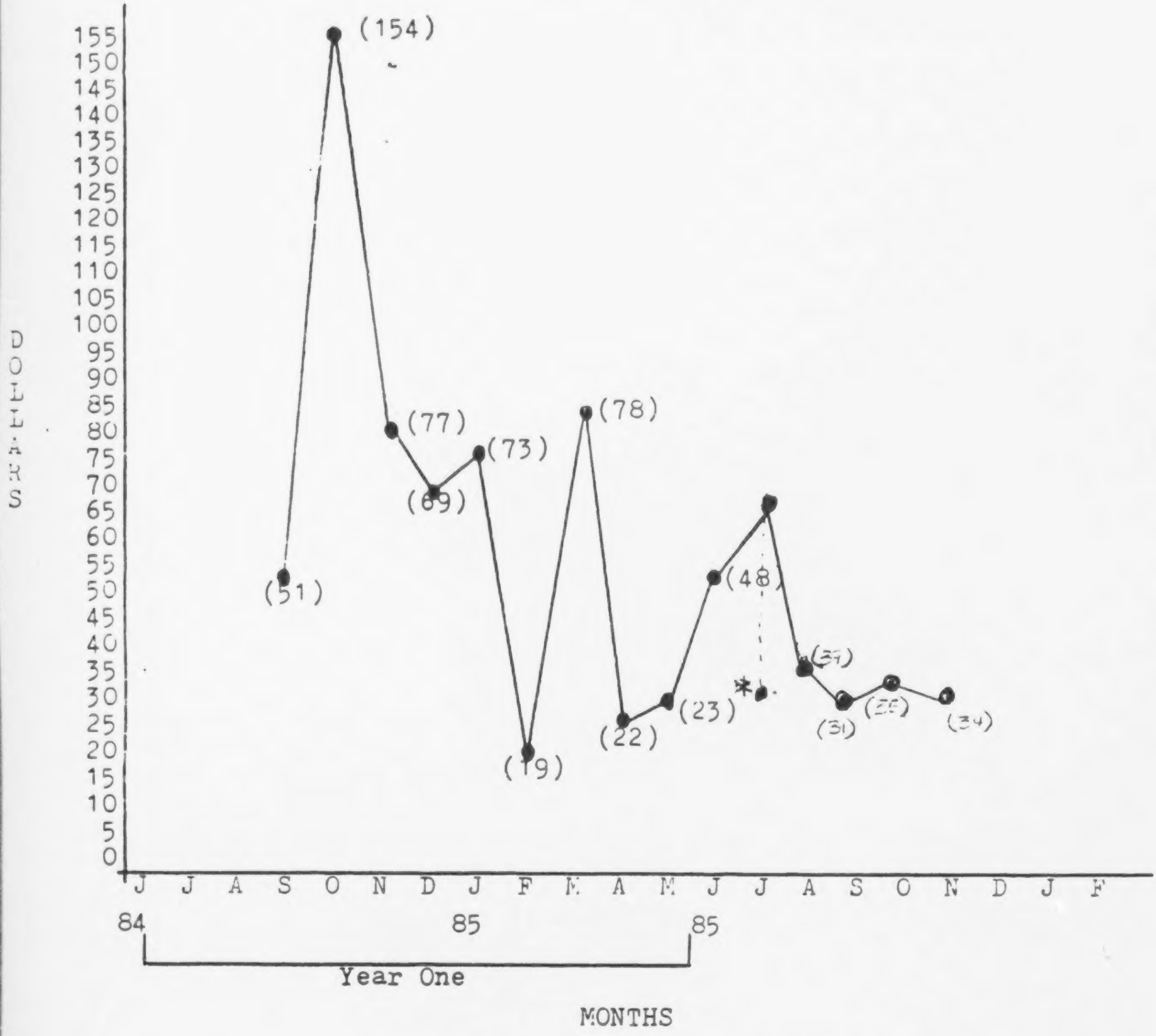
Update July - November 1985

	Days Opened	Clients Served	Participant Days	# of Clients Per Day	Projected # Clients/Day
July	21	19	190	9.05	18
August	22	23	256	11.6	20
September	19	20	181	9.5	20
October	21	24	282	12.8	20
November	19	21	231	12.0	20
Totals	102	51	1,140	10.9	19.6

TABLE 4

COST PER DAY

Total Expenses/Units of Care (Participant Days)



* COST MINUS AIRCONDITIONING EXPENSE

TABLE 5

ANALYSIS OF AVERAGE GROSS INCOME
July - October 1985

	Jul - Oct Actuals	Less Unusual Items	Net Actuals Jul - Oct	Average /Month
Revenues				
Client Fees	$12,890.90		$12,890.90	$3,222.72
Grants	8,370.00	$8,370.00		
Mem Donations	1,175.00	1,175.00		
Genl Donations	1,922.00	1,922.00		
Fund Raising				
Other Income	4,562.68	4,562.68		
Total Revenues	$28,920.58	$16,029.68	$12,890.90	$3,222.72
Expenses				
Consultations				
Gross Salary	$16,644.28		$16,644.28	$4,161.07
Office Exp	49.56		49.56	12.39
Printing	541.57	101.00[1]	440.57	73.42
Postage	304.34	193.00[1]	111.34	27.83
Publicity	451.89		451.89	112.97
Misc Exp	6,584.11	6,584.11[1]		
Legal				
Accounting				
Telephone	528.47	131.00[2]	397.47	99.36
Meal Prep				
Utility				
Insurance	1,481.24		1,481.24	370.31
Rent	9,236.00	7,236.00[3]	2,000.00	500.00
Center Cons	347.61		347.61	86.90
Part Cons	231.74		231.74	57.93
Food	2,067.38		2,067.38	516.84
Payroll	307.67		307.67	76.91
Start-up				
Total Expenses	$38,775.86	$14,245.11	$24,530.75	$6,095.93
Gross Income	($ 9,855.28)		($11,639.85)	($2,873.21)

[1] Conference and special program expenses
[2] Telephone installation
[3] Air conditioning installation

Final Report

Assessment of Disorders Causing Dementia

Office of Technology Assessment

Congress of the United States

The Family Survival Project

April 1986

By Diana M. Petty
1736 Divisadero Street
San Francisco, CA 94115
415/921-5400 or
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In the early 1970s I worked as a volunteer with a group of disabled Vietnam veterans. Most of the young men in the group were paralyzed, but a few were struggling to achieve rehabilitation or adaptation to other physical and mental conditions. Bill, a Marine Corps officer, had returned to California after being shot in the knee during the seige at Khe Sanh. While undergoing physical therapy for his knee, he began to experience blackouts and seizures.

When Bill's blackouts first occurred, he was admitted for psychiatric evaluation. For eight months he was treated for psychiatric disorders without receiving a neurological examination. Over time he experienced more intense seizures more often; brief blackouts occurred every few minutes. He argued that he was not psychotic, and, ultimately neurological testing revealed that he had a form of epilepsy that affected motor-sensory functions. The identified cause was the constant barrage of mortar rockets exploding near him in Khe Sanh. Bill's epilepsy was manageable but severely disabling. It was combat related. Yet it took another seven years for him to be classified "disabled" by the Veterans Administration and eligible to receive disability income--even though at times he had as many as eight seizures each day and frequently could not follow conversations because of blackout periods.

More than any other experience, Bill's case exemplifies for me the "state-of-the-art" for adults with brain damage and chronic brain diseases in the last decade. Although his treatment occurred in the Veterans Administration, what happened to him was common in other health care and social service programs.

The similarities between Bill's problems and those of other persons with degenerative diseases that cause dementia are numerous: the symptoms are often misunderstood, and misdiagnosis is common; communication between psychiatry or psychology service units and medical providers is poor or does not occur; public benefit programs take a wary view of those with "invisible" mental impairment; and society tends to blame brain-damaged patients (and other mentally impaired persons) for causing their own problems.

Bill's case signified to me a horrifying inadequacy of an otherwise rich health care system. But my principal interest at the time was as a journalist and friend; I had no professional involvement in health care. In 1978, Steve Thompson, a health care policy consultant from Sacramento, called me at the San Francisco public relations firm where I worked and asked if I would talk with members of a group who were seeking a project director. I knew Steve's firm held a contract over the previous year to study the impact of brain damage on families and social programs. The group, sponsored by the local Mental Health Association chapter, had received a one-year state mental health grant to set up a family support project and to subcontract with Steve's firm for the study in San Francisco. Four months remained on the group's contract for "The Family Survival Project" and the project director had resigned. Steve believed that at this early stage a writer and publicist with legislative and fund raising experience could help the group more than could a health or social services professional.

I met with three members of the FSP steering committee: Anne Bashkiroff, Chairman, Libby Denebeim, the Mental Health Association's president, and Jane Ophuls, the association member who first brought the subject to the association's attention. A public relations consultant was present, too, as the group planned to publicize the results of Steve's study. I heard about the problems the group wanted to address, answered questions about my background, accepted an invitation to attend a steering committee meeting the following week and left with a copy of the needs study, a few newspaper reprints about the Project and some other literature.

The literature made me understand the group's purpose. I read a feature article about Anne Bashkiroff's efforts to find care for her husband, a victim of "presenile dementia", later believed to be Alzheimer's disease though never diagnosed as that. The article quoted Mental Health Association staff and an attorney about the dearth of services and the misunderstood problems of both brain-damaged patients and their relatives. I read Steve's report and understood what he already knew: a person stricken with brain damage in adulthood fell through the cracks of America's categorically organized services. It did not matter what the individual diagnosis or cause might be. It did not matter if income status or sex or race or age made them eligible for various public programs. What mattered and seemed remarkable was that no program for health care and social services in the United States provided assistance to meet the needs of those with organically-based disorders. Steve Thompson had spent his professional life in health care and mental health care policy. I had spent mine in journalism, politics and community agency public relations. He understood the problem from a "social policy" perspective because he knew a great deal about the reasons. I understood it because I had seen how government operates and had published a county human services directory for three years. I understood because of Bill and because of relatives and friends who had suffered from inoperable brain tumors, strokes, and "senility". In fact, now in my eighth year with Family Survival Project, I have yet to meet anyone who could not tell me about someone they knew, someone they cared about, who had experienced brain damage as an adult.

But as I soon learned, brain damage and its consequences are not easily understood by the public. It seems that the issues are too broad, the problem too common in our lives to be grasped quickly. I believe, too, that the distance and isolation caused by embarrassing symptons, enormous care demands and the long duration of many patients' disorders keeps these issues out of the public's viewpoint which is shaped by a mania for fast-breaking news. When I met the Project's steering committee for the first time, the members struck me as being shell shocked. A group of about 10, half were relatives of a brain-damaged person and half were professionals. Several were both. They knew they were facing a large problem. They struggled with the enormity of the job to be done and the smallness of their project.

The group's history was interesting in terms of successful community action. Nonprofit and private groups frequently identify social problems years before governments and large institutions can act; Family Survival Project was a striking example of solutions following far behind need.

Today, Family Survival Project's annual budget exceeds $1 million. It has a staff of 20, several independent consultants under contract, service provision subcontracts with home health agencies, day care centers, and health and mental health professionals. It has sponsored two landmark bills in California that first established a pilot project to find a model of comprehensive services and now is establishing a statewide system of regional resource centers for families based on that model. It is under contract to the State of California to serve as one of those centers in the San Francisco Bay Area and also to coordinate the development of the statewide program, including social policy research, training, and an information and technical assistance clearinghouse. Its mission is to address the problems that result when chronic or irreversible brain disease and injury occur in persons after the age of 18. It seeks to assist family members and other caregivers; to increase knowledge and understanding of the extent of brain disorders and their impact on individuals, families and communities; and to build new services and programs for this population.

History: The Family Survival Project began in 1976 because Jane Ophuls, a 20-year member of the Mental Health Association's board of directors, received a call from a friend who served on a local hospital's board. The board's secretary, Anne Bashkiroff, was living in a nightmare with her husband. In his form of dementia, he exhibited all of the worst symptoms and care problems. He was incontinent, confused, disoriented to place and time, acting bizarrely, frequently aggressive and violent, particularly when frightened, and, because of his large size, frightening to others. Anne, whose experiences are described in a book by Gail Bernice Holland, For Sasha, With Love (1985, Dembner Books) had been caring for her husband for nearly eight years. He had been admitted and then ejected from several nursing homes in just a few months. She was desperate to find a placement, and no organization or government agency seemed able to help.

Jane Ophuls is the kind of woman who never saw a problem that didn't need her. She cannot bear to hear of a tragedy without doing something about it. She would probably cringe at this description because she does not acknowledge her own generosity. But she brought the story of Anne and her husband to an association board meeting. The board suggested that its community assessment committee, chaired by a social worker with lengthy activist credentials, invite Anne to present a summary of her situation.

By all accounts of those present, Anne delivered an impassioned, highly-charged summation of her life, her husband's illness and the failure of anyone to help her. For one member of the committee, Sue Harris, the act of sitting and listening to this story was nearly unbearable. Sue does not speak easily about her own husband's illness and death, even today; but at the time she heard Anne's appeal she was living through a similar tragedy. Her husband's brain damage was caused by a massive brain hemorrhage from an aneurysm, anoxia, subsequent surgeries, infection, and hydrocephalus--in short, a chain reaction of neurological mayhem. The case was particularly ironic because Dr. Harris had founded and chaired the Psychology Department at the University of California, San Francisco, Langley-Porter Institute. Thus, two sophisticated women, one who had worked for nearly 20 years as corporate secretary to the board of trustees of a major urban hospital and the other the wife of a leading research and academic psychologist, could not--with all their contacts and savvy--dislodge the obstacles to their husbands' care and to their own well-being.

A task force to investigate the problems of irreversibly brain-damaged adults and their families, particularly those of middle income status, was formed immediately by the association. By the end of 1976, several family members, two attorneys, a nurse/discharge coordinator, a psychiatrist, and a social worker had joined it. Although they initially researched the inadequacy of nursing facilities, the long list of problems and needs soon emerged.

With assistance from the association's staff, the group sought publicity for the problems they uncovered and contacted community and political leaders. They formed a support group for other family members and held a community meeting in early 1977 that drew nearly 200 individuals. The task force knew it had discovered something of far-reaching proportions. After meetings with state health officials, they wrote and received the grant for which I was retained. In addition to Steve Thompson's needs assessment study ("Brain Damage: A Diagnosis of Personal Anguish and Social Neglect," Thompson and Associates, 1978), the grant provided funds to publish a handbook of legal and financial information (The Family Survival Handbook), sponsor the family support group, organize a "network" of family members for mutual emotional support, and conduct a public awareness campaign.

FSP did not succeed overnight, nor were its eventual accomplishments the result of being "in the right place at the right time". The organization was in fact the first catalyst to crystallize the issues, enabling other groups to be in that "right place". Early national media coverage, particularly in the Washington Post and on the PBS network, prompted individuals from throughout the country to contact us. The same advice was given to all who asked what they could do: start a group, we said. Most projects for brain disorders existing at that time were allied with university and medical research programs. FSP was free-standing, and it gave a voice to hundreds who were isolated with a brain-damaged relative.

FSP's ability to respond and achieve a new approach to old problems originated in its earliest actions: the decision to include all brain-impairing conditions within its scope; its partnership with the public sector and elected officials; its identification of the family and caregivers--rather than only the patient--as the target client populations; the insistence that income criteria be eliminated from its model programs; and its unwillingess to invent yet another categorically based service system that would ultimately produce other unserved groups and fragment services further.

Reasons for broad scope: In order to understand the reasons for FSP's decision to focus on all brain disorders, a few social factors that emerged during the last decade should be described. These factors required substantial revision in the conceptions about organically-based brain disorders held by the medical establishment, other professions and social policy makers.

First, new technology and research findings burgeoned in the medical field in general and in the neurosciences specifically. Ailments or conditions that caused dysfunction due to brain tissue damage were increasingly acknowledged to have far different diagnosis, prognosis and treatment requirements than other mental and physical impairments. The terminology utilized by medical, mental health and social service professionals to describe neurological disorders has yet to match the scientific developments: a vast and confusing array of terms is employed to describe these diseases and conditions; as many as 20 terms--many colloquial--may be used by practitioners for only one disorder. Problems related to nomenclature and diagnosis were among the first identified in Thompson's study.

Second, advanced medical technology and knowledge meant greater numbers of victims of traumatic brain injury, stroke and other forms of brain damage were surviving. At the same time, technology and modern life styles were increasing the incidence of brain injury and other illness. Expanded medical knowledge and improved living standards enable Americans to live longer, thereby facing a higher risk of degenerative neurological disease and dementia.

The third influence was the trend nationwide to close down large state-run mental institutions in an effort to end the "warehousing" of the mentally ill. As long as confusion over the causes of mental illness, behavior disturbances and personality disorders existed, persons who suffered from an organically based disorder (such as multi-infarct dementia and a variety of other degenerative diseases, alcohol or drug-induced brain damage, and post-trauma, post-anoxia and post-infection impairments) could be treated and housed like other mentally ill persons. With the movement to return mental patients to the community came a growing concern over a lack of resources in those communities for former hospital patients. These factors had a twofold adverse impact on neurologically impaired mental patients. In order to make better use of limited community and state hospital resources, diagnoses were more carefully scrutinized. Now, adults with neurologically (or organically based) disorders were frequently excluded from hospital and community mental health program admission. Recognition of the inappropriate placement of persons with traumatic brain injury, stroke or dementing illness in psychiatric facilities would have been a blessing had local programs been developed to meet their needs. However, those resources were strained by the release of other mental patients into communities, and while brain-damaged patients were screened out of state hospitals, they also were screened out of local mental health programs because of their organic diagnoses.

The visibility to society of brain-impaired adults was hidden longer because of the large numbers of patients who are middle income; but eventually those with the most bizarre behavior problems or violent manifestations had to go somewhere. Their families turned to a system already glutted by other mentally ill and impoverished or solitary (meaning homeless) patients. That system included no provisions for those with "chronic, organic brain syndrome or damage".

Fourth, several new categorically specific programs and systems had evolved in the United States to meet the needs of other groups: the developmentally disabled, persons over age 60, and the physically disabled joined low-income persons and veterans as groups for whom large service systems were designed. As their needs seemed to be met, at least in theory, other populations (or subgroups) with unmet needs emerged. While advocacy groups for other "special needs" populations made significant gains in federal and state policies and programs, no such voice had developed for the brain-impaired adult.

Fifth, the United States had concluded ten years of experience with the new federal medical care reimbursement programs for the poor, elderly and disabled. The results for brain-impaired adults were disastrous, perhaps more so than than for other persons with chronic illness or disability. Because their needs were most often custodial and non-medical in nature and behavioral in character, patient care was not subsidized by Medicare or private insurance beyond acute hospital stays.

Public and private health insurance programs generally have neglected long-term care needs. They have specifically shunned brain-impaired persons, and the financial and care-providing impacts have been particularly onerous: "chronic brain disorders" are specifically excluded from most health insurance policies; reimbursement of post-acute rehabilitative care is often denied because of the "chronic" or "organic brain syndrome" labels; and brain-impaired patients, especially those with dementia, are often denied admission to long-term care facilities based only on their diagnoses and supervision needs. The federal Medicaid program, following impoverishment of the family or individual, remained as the only resort. But Medicaid reimbursement rates lagged behind care costs, so persons who required intensive non-medical supervision and personal care were excluded from Medicaid facilities, as well. The only real long-term care program was the family itself. In many cases, the streets have picked up the slack.

Finally--and compounding all of these factors--was the medical model of service delivery. Not only did this diagnostically oriented system affect financing, reimbursement and care models, it was inadequate to the task of identifying brain disorders. Most were grouped collectively under a few labels. Today, there is no estimate of the true number of persons who suffer from organically based brain impairment. Failure to utilize standardized diagnostic terms and the way "cause of death" data are collected have made it impossible to determine incidence. With the revelation of brain-impaired adults as an unserved population came a complex problem: until public officials can identify the causes and terms for brain damage, no one can gather accurate statistical data. Without such data, no one can know the numbers afflicted nor the full extent of the problems to be faced.

In California, the apparent factors that affected brain-impaired persons were compounded by the existence of an innovative program for individuals who manifest developmental disabilities prior to their 18th birthday. Called the "Regional Centers for the Developmentally Disabled", each major community and geographic region in the State is served by a center that conducts client evaluations, designs care plans and "purchases" services necessary for the care and habilitation of persons with certain specified disabilities (mental retardation, cerebral palsy, autism and similar neurological disorders) that constitute a "substantial handicap".

However, adults who manifest neurological or other handicapping conditions after the age of 18 are not eligible for regional center services. The developmental disability system will be described further in relationship to program approaches below. Here I want only to point out that a model for brain-damaged adults existed, and that its existence and eligibility restrictions helped to exacerbate the anger of those who needed similar programs.

In 1978, I suggested to FSP's steering committee that it could pursue two approaches as an organization to address its already identified generic scope. It could follow the "single disease" approach and become a "Disease of the Month" type group, concentrating on the term "brain damage" or on one or two disorders. Or, FSP could look to the developmental disabilities system and the programs established under the Older Americans Act for examples of broadly based, generically oriented organizations. The steering committee agreed to the broader model primarily because they believed that diagnostic categorization was at the root of the problems they were addressing. Our scope was reinforced by the many state and national public officials who pointed out their frustrations at being "hit up" daily by innumerable causes. They urged us to adopt a pragmatic approach that would represent the largest possible target group.

The fragmentation of services, the categorical approach to service eligibility and delivery, and the problems associated with diagnosis and patient assessment for disorders causing dementia are now well documented. Obviously, categorical program models are major contributors to the fragmentation that causes severe inequities for some patients. The way in which funds are cycled into programs is an insidious aspect of service character. Government funding follows fashionable trends in much the same way as does television network programming. Programs begin to receive government support long after the public grasps the problem to be addressed or knows of the popularity of a given program solution. Grant-making that respects, first, competent grant writing and, second, the reputation of the applicant seems to contribute greatly to the uneven distribution of services, research and system components. These projects follow exisiting categorical models, and recipient financing observes the same models. If FSP could circumvent the more common funding cycles and break the trends of grant giving, then whatever programs were developed for brain-impaired adults might not suffer from the same fragmentation. Government could perhaps be persuaded to respond at the same time as the community.

We examined the results achieved by various disease education and research groups. Their gains were remarkable, but largely within research, treatment, education and creation of specific service units, such as dialysis. The long-term results were a piecemeal service system and continuation of service policy based on elements of the medical model. Concentration on a single disease group, such as dementia, might result in little overall systems change or policy. The most significant factor in FSP's mission was our acknowledgement of the commonality with other chronic illnesses and disabilities in terms of long-term care development and provision.

We were, of course, forced to re-examine the scope of the organization every time a segment of the adult population began to organize. But the arguments in favor of the larger population always outweighed those of focussing on a smaller segment. We felt that every popular disease eventually peaks in the public's mind. We decided to start at the place where we must end up. We decided to be an organization that addresses the social policies that cause fragmentation, categorical eligibility, and service gaps; that addresses a heretofore unrecognized client, the family; and that seeks to avoid the pitfalls of other public advocates during a period of economic austerity and social realignment. By mid-1979, FSP had adopted an ambitious agenda:

> To establish a network of families of brain-damaged adults for mutual emotional support.
>
> To educate the public about the problems that result from brain damage in adulthood and about the service needs of families and patients.
>
> To develop and obtain funding and support for a model of comprehensive, coordinated and affordable services.

To encourage development of services by other groups, policy makers and communities and to change policies that impeded service development.

To establish a data base, possibly the first ever, of information about brain-impaired adults, their families and caregivers, brain disorders, service needs, and service costs.

To train service professionals, the legal profession, paid caregivers and others about aspects pertinent to the care or supportive assistance of patients and families.

To provide a clearinghouse of information and research on brain disorders and service alternatives and theories.

To link up with other allied organizations and professionals, with key involvement by family members, toward broad policy, education and service development goals. "Allied groups" included other health and disease education and research organizations, particularly concerning chronic illness and disability, rehabilitation programs, nursing homes, home health agencies, and senior programs.

Approaches undertaken: The Thompson study suggested a model of service that included centralized diagnostic and evaluation services, information and referral, counseling, legal advice, in-home supportive services, adult day care, and inpatient care. The options for establishing these services included single-agency delivery, such as by a medical center; a pilot project in a community agency with service provider subcontracts; and integration of policies for brain-impaired adults and their families into the agencies responsible for providing or financing each type of service. Thompson proposed legislation that would establish the community agency pilot project, and eventually we incorporated all three approaches.

The first legislation we sponsored was AB 1043, authored by California Assemblyman Art Agnos in 1979. According to his staff, Mr. Agnos analyzed the bill's chances for passage before agreeing to introduce it. He concluded that the bill might not pass in the first year but it would attract support for later approval. FSP reasoned differently. Art Agnos was chairman of the State Assembly's Democratic Majority Caucus, which made him a potent legislator. Before his election he was consultant to the Assembly Select

Committee on Aging. He was also a former social worker and could understand and--more importantly--articulate our cause.

The bill passed each hurdle, with negotiations occurring only over the appropriation. We sought $1.1 million to establish the service components proposed by Thompson, but the Assembly Ways and Means Committee asked us to come up with a program for $250,000, or rather, we were asked what we could do with that amount of money. This action typifies the public policy process where program "designs" are tailored to fiscal expedients.

Jane Uitti, the consultant retained to "work" the bill, and I sat down in a coffee shop with two FSP steering committee members, Frances Morain and Bernard Peeters. We scratched off diagnostic services (too expensive and also usually reimbursable by private and public insurance programs), inpatient services (too expensive and too vast a problem, i.e., in what type of facility and what type of program?), and adult day care (California and the Older Americans Act were providing funds for adult day care in many communities). We then asked ourselves, "what are the greatest problems identified by families surveyed in the Thompson study, our support groups and telephone calls, and documented by such researchers as Carl Eisedorfer, M.D.?" They were the lack of organized, accurate information and advice, the need for emotional support, and the need for home care for middle income persons or those ineligible for county (Title XX) home care and Medi-Cal.

We proposed amendments to Assemblyman Agnos that would establish a pilot program for information, advice and referral, case coordination, legal counseling and in-home supportive services; a nonprofit agency with family members representating all types of brain damage on its governing board, would administer the project. The bill passed and went to the Senate where it passed easily.

We had to overcome three problems to achieve the signature of governor Edmund G. "Jerry" Brown, Jr. One was the inability to find a generic state agency that would agree to oversee the project. We wanted the Office of Statewide Health Planning to take the program, but its director did not believe the office had enough project management capability. The director of the Department of Rehabilitation offered to take it if no one else would, but the state's vocational rehabilitation programs reached only a small percentage of the brain-injured population. No other department including Aging and Health Services, was interested. The Department of Mental Health, which had administered our first grant was the only appropriate state agency that wanted the new project, and that's where AB 1043 was placed. The second problem was the State Department of Finance position of opposition which was based on the erroneous belief that the bill duplicated other state efforts. The Finance Department stated that these clients were served in the Department of Developmental Services; we succeeded in describing the distinction between brain-damaged adults and developmentally disabled clients. Our final obstacle was the governor who was in the middle of his "era of limits" administration. Brown was opposing all new programs that would require new general fund appropriations. However, one of his legislative aides was married to a man who had suffered aphasia due to a brain injury. She convinced the governor of the very great need for our program. When he then countered that the proposed project was too small, she persuaded him that anything, even a pilot project, was a necessary start.

FSP's legislative efforts at this time faced incredible odds in 1979. About 1,300 family members and providers were on our mailing list, and most were in Northern California. Few proposals can succeed in California without the large voting block in the south. I studied state legislative district maps and compared cities where legislative votes were needed to the addresses in our card files. We wrote letters, and in the evenings the steering committee and other volunteers called family members in targetted cities. We asked support group participants to contact their relatives in other parts of California. The Senator from Whittier, a Republican, supported our Democrat-sponsored bill; he heard from two constituents and a hospital administrator in his district; he was convinced of the need for such a project in his home territory. He did not know that the constituents were the mothers of FSP's secretary and a steering committee member; the hospital was the facility where another steering committee member had placed his wife who was comatose. Creative grassroots lobbying.

Five years later, when in 1984 we sponsored AB 2913 to establish the statewide program of regional resource centers, more than 200 organizations wrote letters of support. Assemblyman Agnos, who again authored the legislation for us, said that he had never received as much mail on any issue as he did in support of AB 2913--and he had just authored a controversial gay employment rights bill which was vetoed by the governor after several days of deliberation, front page coverage and heavy lobbying by groups on both sides.

Why, then, were we able to pull the rabbit out of the hat in 1979? The Alzheimer's Disease and Related Disorders Association (ADRDA) had not yet formed (FSP would join others in proposing its formation later that year). Alzheimer's was not even a common diagnostic term in California in 1979 and would not be until at least 1983. The Spivak family had not yet established the National Head Injury Foundation. The national organizations for other neurological disorders were targetting research, education and client independence. They were not focussing on the difficult, severely cognitively impaired patients yet. Worst of all, without concrete data available about the incidence and prevalence of brain damage in the United States or California, there was no way to document who was and was not receiving services and how much those services cost or would cost.

By calling on every pivotal vote-maker in the State Capitol, however, with a small, presentable and articulate group of family members, we were able to convince enough legislators and staff members that one small pilot project for one year would not hurt and just might help. We did not send busloads of constituents to the Capitol, avoiding the risk of angering already overworked legislators. Our message appealed to both parties and to fiscal liberals and conservatives. We were not trying to throw a lot of money at a problem, and we did not propose that the state be responsible for every brain-damaged person (which would have created an entitlement and open-ended program).

Most importantly to FSP, we could give some immediate assistance to those who contacted us and could begin our most critical strategy: the building of a public voice for future wider efforts. Successful sponsorship of state legislation also gave FSP public recognition, credibility with other advocacy groups and professionals, connections in state agencies and the Capitol (very helpful whenever state payments on our grant were delayed), and heightened visibility among the state's service proponents.

In 1980 we received the contract to implement the pilot program, and we would return to the Legislature in 1981 and 1982 to continue and augment its funding. By then, the Department of Mental Health had incorporated the project into its base program and given us additional funds to set up a statewide information and training clearinghouse. The funds were token, hardly enough to buy file cabinets to house our information; but the gesture sanctioned the time we spent helping families and groups outside the San Francisco Bay Area.

We operated the pilot project for five years, until June 30, 1985, feeling our way to develop the best program possible. Although we fine-tuned and revised components of the program during that time, the essential model remained the same. Along the way, other new efforts came to our attention and we began to develop "colleagues". A few of the efforts we tried and their outcomes included:

A consultant for families: Our original project design established a "program coordinator" and "social worker" for in-home supportive services to work collaboratively with families. Outreach would be conducted by our program assistant (a permanent staff position), and overall management would be provided by FSP's executive director. However, FSP was at that time still a special program of the Mental Health Association and was in the process of setting up a separate corporation. The hiatus made it difficult for the new FSP board to raise money to fund other activities, and so the pilot project was organized to run itself. The program coordinator was turned into a project manager; the social worker handled only home care cases. Kathy Kelly, the project assistant, filled in with support groups, training and outreach; I turned my attention to grant writing and organizational development. A committee of the board, headed by Sue Harris, held everything together.

By the end of the first year, the board asked me to take over management of the project, and the staff identified the original component--someone to be the ongoing contact and planner with families--as being a critical need, the glue, so to speak. Families needed to call frequently and talk with someone familiar with brain damage and its complexities. Also, we were learning that the family situations were ever-changing, meaning that either the patient's status, or the caregivers' status, or other ingredients, were rarely the same from one month to the next. FSP had to be become the family's resource during all its crises and help to forestall emergencies whenever possible.

We invented a new position, the "family consultant". The consultant would work as a professional planner and problem solver with families. FSP's involvement was important to many of the families we helped, even after the brain-damaged patient was placed in a facility or died. Our role was to teach caregivers and other family members to become their own case managers, to support them with information and reassurance, to be a sounding board. Our staff members would help identify problems, recommend possible solutions, and research community resources and publications. The family members would carry out their own plans. When needed, the family consultant would confer with other professionals and mediate on behalf of a caregiver or patient. But never would FSP's services supplant the family or be delivered against a patient's wishes.

Examples of the mediation role are numerous. In one case, the family consultant brought a family physician, neurologist and psychiatrist together to meet with family members when the three practitioners were recommending counter-productive treatments for a dementia patient. In a another case, the family consultant persuaded a northern California hospital administrator not to release a semi-comatose accident victim until the family, who lived in southern California, could locate a convalescent facility. When a stroke patient's brother appealed to FSP to help prevent his brother's further physical decline due to cessation of Medi-Cal reimbursed physical therapy visits, FSP staff persuaded the nursing home's administrator to permit an aide to supervise simple physical therapy exercises at no additional expense.

Until 1983, the family consultation process was limited to three sessions because of limited funds and staff. The arrival of a a licensed clinical social worker on staff and the doubling of intake each year (from 200 in year one to 2000 in year five) caused us to make consultation services more flexible, ranging from long-term care planning to individual counseling.

Professionals were also in danger of "burning out" in their attempts to help patients and families. One memorable case brought to us by the State Department of Mental Health involved a hospital discharge planner who worked for five months, contacting hundreds of facilities and programs, in her unsuccessful efforts to place a severely brain-damaged woman in a skilled nursing facility. The woman required total care and was verbally loud and disruptive. She was on Medi-Cal and her only living relatives were in Canada. The hospital administrator was pressuring the discharge coordinator to get the patient out of the hospital. The coordinator was as emotionally exhausted as many relatives. Our education programs were soon tailored to help paid caregivers as well.

IHSS...it works, but is it too costly? In the first year of the pilot project, we provided in-home supportive services to 52 San Francisco families for an average monthly cost to the state of $745. More than 70 percent of our IHSS patients had a disorder causing dementia or other progressive disease, 36 percent had suffered strokes or other types of vascular accident, and 40 percent had at least two neurological diagnoses. Our social worker conducted a home assessment, worked with several home health agencies under contract to FSP and arranged for the appropriate services in the homes. Home health aides, 24-hour attendants and transportation were used the most. The program was a great success. Families and home health providers agreed that the program kept patients out of facilities and eliminated unnecessary acute hospitalization. Several assumptions about home care for brain-damaged adults proved wrong: behaviorally disturbed, combative adults could be cared for at home if aides received training in patient and behavior management. Very few cases required skilled nursing care--personal care was adequate for home maintenance.

But for a few severely impaired patients the program was costly when compared to some skilled nursing facility placements, costing FSP more than $2000 a month for 24-hour attendent care. Although we believe that the cost of a program should not be the deciding factor in home care and facility placement, we did believe that these costs were too high for the limited funds provided under our pilot project. But little cost-of-care information was available. We were asked frequently by state officials to compare our home care costs to other traditional settings. The only method available to us, via a hand calculator, was to determine where our patients would be placed without IHSS and who would pay, e.g., the family, Medi-Cal, etc. Our calculations showed that in less than three years, the state would pay nearly $300,000 more for these patients than our program would cost. The cost computations were so rough, though, that I'm embarrassed when offícals quote the results.

Another problem with the IHSS program was it's availability only to San Francisco County, due to limited funds; all of our other services were offered in six counties. Somehow we needed to help the many caregivers in those areas who needed relief. In 1982, I proposed to the board that we change our in-home supportive services program to a "respite brokerage". Our IHSS findings showed that families believed 10 hours of assistance per week was enough relief to keep the patient at home. This became the foundation for our respite program.

Respite Program - band aid for caregivers: We initiated the respite program as a subsidy, with family copayments based on income. It was importent not to limit the length of time for participation (duration), but we could not risk running out of funds in mid-year, either. We capped the subsidy at a level that would pay 10 hours of home care weekly ($380/month in 1982, $425/month in 1986). On average, the families contribute about 23% of the cost. We also instituted contracts with day care centers to provide out-of-home programs for those families who preferred them and whose patients functioned highly enough; our vouchers can provide two to four days a week in day care. Transportation was available to take patients and caregivers to out-of-home activities. The focus of the service is the caregiver, not just the patient, as a service recipient. We can now serve more than 100 families annually, but the need is greater and inexpensive options are needed. We are developing other types of respite: volunteers, inpatient beds, home-aide-hiring registries, and so on. This year, we are beginning to reimburse family members who hire aides privately. We also refer to attendant programs in other community agencies such as Independent Living Programs and Catholic Charities.

Real attorneys for real problems: After patient care, families had always identified legal and financial help as the most significant need. Not only did they want advice, however, they wanted competent advice. Finding attorneys who could provide competent counsel on estate planning, taxes, probates and other private issues was difficult enough; finding attorneys that would work "cheap", were willing to forego fee generation from cases, and were confident enough in their own skills to confer with a variety of other legal and social service professionals was nearly impossible. We failed at attracting interest from county bar societies; the state bar would not let us charge fees for legal services; legal aid services were unfamiliar with the legal concerns of middle-income families. Finally, at the suggestion of a foundation director, we asked a group of attorneys and social workers who specialized in financial management to form a planning committee. They helped us establish subcontracts with attorneys to provide screening consultations with families; we established a list of specialists to whom the attorneys could refer for follow-up work, and we continued to include legal and financial workshops in all family and professional educational activities. A key component was to establish one of our social workers as a screener for concerns, particularly related to public benefits and insurance. The primary goal of our legal consultation program, in concert with our social worker, is to help families conserve resources and plan for the legal and financial consequences of long-term care.

FSP as social change agent: The last important aspect of our pilot program was our work as social change agent: public policy development, service coordination, technical assistance and community organizing activity. More than any other aspect of FSP, these activities make it unique. All of our efforts were designed and carried out to encourage the development of programs by other organizations. For example, we participated in the formation of ADRDA (regrettably, our mission to serve those with other brain impairments prevented FSP from becoming a chapter), and we helped develop local Alzheimer's respite centers, an Alzheimer's family support program sponsored jointly with a local hospital, the Brain Damage Coalition of California, more than 100 support groups and numerous service programs.

The concept of mutual effort and collaboration is the concept behind AB 2913 (Chapter 1658 of 1984). The new law establishes regionally based resource centers to assist families of brain-impaired adults and professionals statewide. Modeled after our pilot program, flexibility is built in to allow each region to develop its own services based on community needs. The right community fit is assured by placement of the centers in nonprofit agencies and requiring project advisory councils. The centers' goals are three-fold:

1. To obtain comprehensive, coordinated public policy for adults with brain impairments;
2. to ensure the existence of an array of appropriate programs and services for brain-impaired adults and their families; and
3. to place a high priority on utilizing community resources in creating opportunities for families to maintain a brain-impaired adult at home when possible and in other community-based alternatives when necessary.

To achieve these goals, Regional Resource Centers must carry out the objectives specified in Chapter 1658:

a. Provide directly or assist families in securing information, advice, and referral services, legal services and financial consultation, planning and problem solving consultation, family support services, and respite care services;

b. Provide centralized access to information about, and referrals to, local, state, and federal services and programs in order to assure a comprehensive approach for brain-impaired adults, their families, and caregivers;

c. Assist in the identification and documentation of services needs and the development of necessary programs and services to meet the needs of brain-impaired adults in the geographic area;

d. Cooperate with the Statewide Resources Consultant and the Director of Mental Health in any activities which they deem necessary for the proper implementation of Chapter 1658; and

e. Work closely and coordinate with organizations serving brain-impaired adults, their families, and caregivers in order to ensure, consistent with requirements for quality of services, that the greatest number of persons are served and that the optional number of organizations participate.

Chapter 1658 placed responsibility for coordinating services to brain-impaired adults and their families, and relevant programs for professionals, in the Department of Mental Health. Statewide coordination of several functions is to be undertaken by a nonprofit agency as the "Statewide Resources Consultant" under the Department. In 1985, FSP's service program was designated the first Regional Resouce Center serving six counties in the San Francisco Bay Area. FSP also became the Statewide Resources Consultant to the State of California. As the consultant, FSP:

develops and coordinates statewide information, technical assistance and training about brain damage, the problems it causes and services needed;

helps plan and set up the Regional Resource Centers throughout the state to provide services to brain-impaired adults and their families, and to assist these Centers in building additional local resources;

helps secure greater federal and private participation in financing of services;

conducts research on the extent and consequences of brain disorders and needed public policy reforms, aids in designing a classification system and nomenclature, and makes recommendations for population and epidemiological studies.

The law defines "brain impairment" as "significant destruction of brain tissue with resultant loss of brain function". Both injury to the brain and degenerative brain diseases are included in the definition. Examples given in the statute include: Alzheimer's disease, multi-infarct disease, Parkinson's disease, Huntington's disease, stroke, traumatic brain injury, post-anoxia and post-infection damage, tumors and hydrocephalus.

Under Chapter 1658 service eligibility cannot be based on a client's income. Persons who are eligible for Department of Developmental Services and other public programs cannot receive the same types of services through Regional Resource Centers, although Resource Centers can help clients find those programs.

Chapter 1658 appropriated $1.1 million from the state general fund to the Department to begin implementation of the law in the first year. The Department and the Statewide Consultant are required to coordinate their efforts with those of the California's Torres-Felando Long-Term Care Reform Act and Linkages programs and with other legislative mandates in the aging and long-term care field, as well as with other state agencies to ensure that services are not duplicated.

Comparison to other statewide and regional programs: FSP studied several program models before developing the approach taken in Chapter 1658.

Most notable were the previously described Regional Centers for the Developmentally Disabled, the Area Agencies on Aging under the Older Americans Act, the Protection and Advocacy Agency for Developmental Disabilities, and Health Systems Agencies. The Regional Resource Centers for Brain-Impaired Adults and Their Families are most like the Regional Centers for the Developmentally Disabled in that they are central resources, located in nonprofit agencies, where clients and providers can receive a variety of services and assistance.

California's State Department of Developmental Services manages funds for the Regional Centers for the Developmentally Disabled; a statewide council advises on matters pertaining to the system and to program development; a network of regional Area Boards reviews programs locally and provides technical assistance. Several communities also sponsor local citizen advisory groups on developmental disabilities. The Protection and Advocacy, Inc., program provides representation for those persons denied services and appeals system policies.

While the Developmental Disability program provided a model for delivering an array of services to the older, brain-impaired population, there were problems in the approach that we sought to avoid. The Regional Centers are entitlement programs that provide case management services to individual clients, utilizing open-ended purchase of service from "vendors". The costs are high and growing, and critics question whether the parents' roles have been supplanted. California's diagnostic eligibility definition--which differs from the federal functional definition and results in denial of service to some who suffer brain damage before age 18--is also challenged.

Assemblyman Agnos and FSP adopted the client needs review and planning model, utilized vendor selection methods and copied the technical assistance role of the developmental disabilities service system. But we capped the cost of our program, made our centers' services those of resource information and counseling rather than entitlements, emphasized that other public programs must be employed first, and continued with our case coordination--rather than management--concept.

The Regional Resource Centers for Brain-Impaired Adults and Their Families are like the Area Agencies on Aging and Health Systems Agencies in their citizen advisory, planning and needs assessment roles. They are not grant-making or monitoring agencies. Protection and Advocacy, Inc. provided a valuable example of a nonprofit agency established by government to manage a program. However, legal representation of clients was specifically excluded from Chapter 1658 at the request of legislators.

Reasons for success and obstacles: Comments on factors that contributed to FSP's success and some obstacles have been included above when relevant. In summary, I think the reasons for our success include:

1. Emphasis on the family, in addition to the patient, as a target for services. Also, our ambiguous definition of "family" to include neighbors, friends, distant relatives and "significant others" has made the program adaptable to California's varied population groups.

2. The motto "to support the family, not supplant it", carried out in our programs by avoiding case management as a service has made the program palatable to family members and public officials. Simply stated, it makes people feel less anxious about our intent.

3. Our recognition of cost limitations and the need to build cheap

solutions makes FSP popular in the state Capitol. One legislator has frequently said that "FSP is a good buy". Our organization--and other groups seeking our help--have felt the stress of our financial limits. But few state-funded programs can boast of doubling intake annually, reaching more than 25,000 individuals through education programs, and sponsoring two landmark bills while increasing our public funds budget by only 12% over five years.

4. The integrity not to publicize our services when waiting lists existed limited the potential to anger those in need of help.

5. Understanding that brain impairments were part of a bigger picture in long-term care provision and financing, we can one day wind down. Few nonprofit agencies have that goal in mind.

6. Lack of fear of others. FSP is rarely accused of committing some sins believed to be common in the nonprofit community. Understanding that brain impairments are part of a bigger picture in long-term care provision and financing, FSP strives to understand other local groups and communities and to minimize turf battles. Rather than attempting to provide all needed services, we urge other groups to develop programs. We say in our literature that the complex problems caused by brain damage require creative solutions, which means that we must work with others to stretch limited funds and opportunities.

7. The board of directors. During the first four years of its existence, Family Survival Project was comprised of a dozen

> hardworking family members, professionals and community activists. Paid staff was limited to part-time assistance from the association until the Project's first grant enabled the hiring of two employees. All decisions were made by or with the steering committee. Members devoted long hours as office volunteers, led the support group, testified in the Capitol, called family members in the evening to offer emotional support, and argued over policy decisions. Even with the growth in funds and staff, the overall direction and program decisions of FSP remain the province of the board.

But numerous obstacles were encountered.

1. The professional community at first was disinterested. We found the medical profession's disinterest to be foremost, but not unique. Brain-damaged adults were viewed as an impossible patient population. In fairness, many other needy groups (the homeless mentally ill, juvenile criminals, etc.) were highly visible. The problem was so great that I still remember vividly the first neurologist who invited us to speak to his staff and the first general practice physician who referred a family. Hospital discharge planners, county home care workers, community geriatric mental health workers and rehabilitation specialists were the ones who helped break down professional apathy. They knew as well as, probably better than, families where services broke down.

2. Public officials feared (and still fear) the so-called "tip of the iceberg". One analyst even used that language in a memorandum to the

state director of health services. The lack of incidence data and service cost data intensifies rather than allays these fears. In 1986, fiscal analysts in Sacramento are still asking for needs projections "before we're spending millions on this population and it's too late to get out."

3. Our complex messages and lower local visibility during times of heightened state or national focus also posed problems. We do not offer many pithy slogans. "Experts on brain damage and all its ramifications" doesn't make good copy. A two-year public relations campaign and AB 2913 are addressing this problem, however. Doing so is important to our ability to raise private funds for programs and to provide valuable help for those in need. We've been in business long enough to see changes in attitudes--"caregiver" replaced "caretaker" and "Alzheimer's" replaced "senility". Patience and persistence will pay off.

4. Lack of affiliation with a University or Medical Center. Ironically, FSP was created because no university or medical center in Northern California was filling this role. However, without an affiliation with such an institution, FSP did not have the credentials to obtain research grants or gain access to professional journals to publish results. To remedy this situation, funds through AB 2913 and other grants now enable us to undertake joint projects with the University of California, San Francisco, the Northern California Alzheimer's Disease Center, Mt. Zion Hospital and Medical Center, and faculty of the University of Southern California.

Challenges for the Future: FSP and other programs serving adults with dementia are presented with many challenges in the future. The principal issues will be the inclusion of our client populations in long-term care programs, the financing of that care, and the ethical and legal questions concerning termination of life, patient management, and rights of the cognitively impaired adult.

FSP's immediate challenges involve the implementation of AB 2913. We have until 1987 to set up the Resource Centers and must negotiate annually with the state for budget augmentations to meet the growing caseloads and work of each center. The requirement to establish uniform standards and procedures for our programs can result in a difficult period for those who have worked under flexible, innovative guidelines. This is a problem for all professionals working with those related to a patient with a disorder causing dementia. As we succeed in reaching our lofty goals, both in the realm of research and that of service delivery, we confront pressure to become more routinized and adopt professional standards.

The topics of professional standards and systematic service provision always raise the traditional conflicts between "direct service personnel", "policy makers" and "administrators/planners". At FSP, these dynamics are being closely watched: half of our staff are currently employed in the family service program and half in statewide clearinghouse, policy and development activities or administration. The tension between each group is palpable when discussions over goals and resource utilization occur. We strive to make each recognize its need for the other. The confusion over roles among participants occurred once before, when the organization's volunteers and board members first felt less needed as the agency's staff and programs grew. Actually, a different type of involvement was required, but for a while it felt to them that they might lose touch with their own organization.

We must also work to balance the government's desire to lower or limit costs with our knowledge of this population's unmet needs. To date, FSP has been able to convince the State of California that we are not taking on the whole world (i.e., all brain-impaired persons and their caregivers). Rather, our programs help individuals, families and other private and public agencies create options that government has not provided. The fact remains, however, that costs will occur if these patients are to be fully served, and those costs will be higher than most public officials are currently willing to support. We hope that California's Regional Resource Centers will contribute to the growing effort to change their minds.

EVALUATION OF A 24 HOUR CARE SYSTEM FOR PERSONS WITH ALZHEIMER'S AND RELATED DISORDERS

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Evaluation of a 24 Hour Care System for Persons with Alzheimer's and Related Disorders

Introduction

For the past several years persons with Alzheimer's disease and related disorders have been cared for either at home or when this is no longer workable, in nursing homes.

Prior to the advent of Medicare/Medical, many of these patients were cared for in state hospitals. The move from the state hospital system to nursing homes was intended as a return to the community. In fact, in California at least for most patients with Alzheimer's disease and related disorders, the result has been a more severe confinement. (Collins, E.,1963; Scott, T., Devereaux, C., 1963)

In California a typical nursing home is 99 beds, staffed 1-13 during the day, 1-20 in the evening and 1-30 at night, and has multiple unlocked doors with some of these placed so that observation is unlikely. Add to this the fact that at the nursing assistant level personnel turnover typically exceeds 200% and in other positions turnover is still in excess of 100%.

Add to this, even with some valid attempts of improvement, the fact that the decor is at best like a good motel and at worst, grim and institutional, that the environment is illuminated at all times, that there are almost always the moans and groans of those in pain, the frightened and psychotic, and then place in that environment a person afflicted with Alzheimer's disease or related disorders. Small wonder that the Senate Subcommittee on Long Term Care, 1974, concluded that "Public policy has failed to produce satisfactory institutional care - or alternatives - for chronically ill older Americans. Todays entire population of the elderly and their offspring suffer emotional damage because of dread and despair associated with nursing home care in the United States today (p.iii)"

The nursing home situation in the last 12 years has not improved for dementia patients. Picture a person with Alzheimer's disease or a related disorder such as Pick's disease entering that environment. If the patient is ambulatory on admission it is not surprising that they attempt to leave or "wander", it is not surprising given the environment and staffing picture that the institutional response is to restrain the patient in a wheelchair and to administer psychotropic medications.

But, the effect of this on a person with failing memory unable to explain to themselves why they are confined to a chair amongst strangers in strange and unpleasant surroundings is devastating. The experience would produce psychosis in a person with intact cognitive functioning. We believe this also occurs or is facilitated in persons with Alzheimer's and related disorders. Additionally in older persons another result of confinement is a hastening of the deterioration of muscle in legs, back and hips and the ability to ambulate is rapidly lost, the process is identical but somewhat prolonged in younger patients.

South Coast Institute for Applied Gerontology was organized as a response to the tragedy of nursing home care for Alzheimer's disease patients. It had been noted during a series of interviews with families during or shortly after admitting a relative to a nursing home that they did so in most cases only after their physical, emotional and mental reserves were exhausted (Sands, D. and Bjorklund, L., 1982). It seemed reasonable to assume that with additional support they would continue in their caregiving roles. In March, 1980, South Coast Institute for Applied Gerontology opened Harbor Area Adult Day Care Center as a program specialized in the care of persons with Alzheimer's and related disorders (Sands, D. and Suzuki, T. 1983; Sands, D., 1984).

The Center was opened initially on a 2 day per week basis with 6 clients. One of these clients was a new resident in a 6 bed board and care home, the Woods Guest Home. The operator had heard of the Center through initial publicity and had told the daughter of a potential resident that her mother could be admitted if she also attended the new day center. The woman was 60 years old and in the fifth year of a dementing illness marked by delusions, memory failure, minimal ability in activities of daily living, agitation and profuse verbalization. Between the Board and Care home and the day center we managed to maintain her for months and at that time she went on to a nursing home. Over the last 6 years Harbor Area Adult Day Care Center has continued to work closely with the Woods Guest Home and for some time all of the residents of the home have been afflicted with Alzheimer's disease or a related disorder and simultaneous clients of the day center.

In 1984 the center developed a working relationship with a second Board and Care home, Autumn Cottage, operated by Judy Belman, R.N. This home opened with the intention of providing care to persons with Alzheimer's or related disorders and of working in conjunction with Harbor Area Adult Day Care Center.

In March, 1985, Ms. Belman began work at Harbor Area Adult Day Care Center three half days as a nursing consultant, a part of this position was to serve as a consultant to Board and Care homes. During 1985 we saw that the other homes could also care for more difficult patients with the back up of a registered nurse as a consultant.

A Table which shows the living situation, days of attendance, potential fee and amount discounted on an ability-to-pay basis is presented below.

TABLE I

1985 BREAKDOWN OF SERVICES:

ATTENDANCE, LIVING SITUATION, FEE, LOCATION AND SEX

COMBINED REPORT

Costa Mesa	Newport Beach	Irvine	Huntington Beach Fountain Valley	All Other •
48	31	17	60	15

• Report on Individual Cities Available by Request

Client	Number	Days	Fee	Scholarship	Percent Paid
		Living with Spouse			
Women	17	1,066	23,648	4,193	82
Men	43	2,104	45,497	11,143	76
	60	3,170	$ 69,145	15,336	78
		Living with Children			
Women	58	3,538	76,942	19,456	75
Men	7	797	17,555	10,667	39
	65	4,335	$ 94,497	30,123	68
		Board and Care			
Women	31	2,134	47,312	21,638	54
Men	3	542	12,040	0	100
	34	2,676	$ 59,352	21,638	64
		All Other			
Women	10	917	19,876	14,589	27
Men	2	13	169	0	100
	12	930	$ 20,045	14,589	27
		Total			
Women	116	7,655	167,778	59,876	64
Men	55	3,456	75,261	21,810	71
	171	11,111	$ 243,039	81,686	66

In 1985 South Coast Institute for Applied Gerontology was designated as an Alzheimer's Day Care Resource Center of the State of California. As a part of the proposal for that designation we formulated our Philosophy of Care which is presented here. Our Philosophy of Care draws heavily on the work of Dorothy Coons (1978) and Leonard Gottesman, (Gottesman, Quarterman and Cohn, 1973).

Philosophy of Care (Sands, D. 1985)

I. Dignity of the Person

A core assumption for us is that dementing illnesses such as Alzheimer's disease do not in some way obliterate the person. They do limit with progressive severity a persons ability to share their life experiences and to respond to family members and others when they share their life experiences. The stresses and strains experienced by caregivers are seemingly unnoticed by the patient (Reifler, et.al., 1981). On the other hand, the patients experiences of losing cognitive abilities, emotional stability and social contact are locked inside leaving caregivers to guess at what their loved one is thinking and feeling.

This limit of the ability to share interpersonally is probably central in leading some persons to conclude that a person afflicted with one of these diseases is no longer there or has ceased to exist as themselves.

This is a philosophical and/or theological assumption. There are no scientific data available to address this issue of whether the person is still in some fundamental sense existing as themselves or what the quality or value of that existence is. Emil Brunner, (1952) a Swiss theologian, offered the following thoughts. "True humanity is not genius but love, that love which man does not possess from or in himself but which he receives from God, who is love. True humanity does not spring from the full development of the intellect, but it arises through the reception, the perception, and the acceptance of the love of God."

We are impressed from our day to day vantage point (with 100's of cases of persons afflicted with these illnesses) by the richness of individual differences and by the still unique contributions that each patient makes to this community. A basic need for the Alzheimer's patient is recognition.

II. Normalization of Life

By normalization of life we mean that the social and physical environment still makes demands and offers choices such that the afflicted person is offered some challenge and has the opportunity to find meaning through their activity. The opportunity to maintain some degree of control both perceived and actual is a key clinical issue (Langer and Rodin, 1976; Schultz, 1976; Sands, 1978; Suzuki and Harris, 1984). Research has shown that persons who are able to perceive themselves as in control do better cognitively, emotionally, and socially. Research has also shown that persons perceived control is closely related to the actual control they experience (Suzuki and Harris, 1984).

The cognitive limits imposed by Alzheimer's disease make it progressively more difficult for an afflicted person to interact with the environment. As the person begins to fail to be able to drive a car, to manage a checkbook or maintain a household, then others in the environment are drawn in to assume their responsibilities. One possibility is that other persons will assume responsibility in such a way that "excess disability" is created.

That is caregivers begin to do things for the patient that they could still do for themselves, (Strauss and Glaser, 1975). Of course the opposite tendency is also highly likely, caregivers will expect patients to carry out functions that they are incapble of fulfilling.

In a situation where excess disability is a high potential event and where actual abilities are declining; a continuous assessment of an afflicted persons maximum degree of independence is required to maintain a proper approach in caregiving.

III. Clinical Implications

Caregivers and patients tend to choose to maintain a common life space. Remaining in a home setting with family is most often the optimum state of affairs in terms of the dignity of the person and normalization of life. Therefore, our primary effort is on sustaining familial caregiving systems.

By providing the family member with a break through day care, and an opportunity to resume activities which have sustained them in the past (golf, club meetings, church, shopping, work, etc.), we sustain them in their caregiving.

By providing the afflicted person with an opportunity to be out and about in an environment which does make demands on their abilities and where they are given an opportunity to be useful to themselves and others then we are sustaining them cognitively and emotionally and in some cases seeing them improve.

In most cases at some point the family is no longer able to sustain home care. If this occurs at the point where ambulation is no longer possible for the patient then nursing home care or home care with appropriate assistance from a home health care agency is appropriate.

If the family is no longer able to sustain home care and the person is still ambulatory and relatively healthy apart from the dementia then our recommendation is placement in a small board and care home. In a 6 bed board and care home the person is still continuously known to the staff. The staff may remain unknown to the patient by name due to memory failure. They are still living in an environment they recognize as a house and in some cases identify as home, and are still able to maintain involvement in day care as an outside activity.

The primary care focus in this continuum remains the patients need for structure, recognition, and reorientation to their situation. The bottom line here is maintaining the patient in the least restrictive setting possible.

Our philosophy of care assumes that we are benefiting from our sharing in the lives of the patients and their families. In the most obvious way the families and the patients are our customers and therefore the heart of our being here. In another sense they teach us how to do the things we do. Through a sometimes painful and sometimes humorous process of trial and error we learn from them how to operate a therapeutic milieu. And further, the families and patients are teaching us something about ourselves, as people, above all that human suffering is difficult but its not without meaning or value, neither is it something to be ashamed of or to be hidden away.

PROGRAM ISSUES

Since the majority of Alzheimer's patients are ambulatory and active they require space to move around in. The Department of Social Services Regulations would allow us to have 54 patients in Harbor Area Adult Day Care Center as it is and 99 patients if we modified the bathrooms.

We requested licensure for 40 and after operating at that level throughout 1984 we feel we were right in that decision. Our space allows patients a high degree of freedom of movement.

With regard to wandering we attempt to understand each patients purpose in moving about and either assist them in realizing it or reassure them it will happen (Snyder, Rupprecht, Pyrek, Brekhus and Moss, 1978) or all else failing give them space when they need it and observe and try to understand.

With regard to choice, or maintenance of control we operate 2-3 program events simultaneously and also have another option which is moving in and out of the events or sitting about outside on benches and watching the activity around them. At transition points, e.g. end of lunch, persons not involved are encouraged but not pushed into participating in the next activity. Outings are another aspect of our program. With rare exceptions, all of the patients enjoy going to a park or the Balboa Pier. This has proved to be the bottom line in reducing agitation for the most disoriented patients.

Incontinence is another frequent problem with persons suffering from Alzheimer's disease. Becoming sensitive to the signs which indicate a need to use the bathroom on a case by case basis can prevent many incidents. Nevertheless accidents do occur and staff need to be prepared and trained to deal with them. In our Center all staff members including the Director are involved in this aspect of care. In addition we have registered nurses who provide training and who observe for and treat related skin problems.

A comprehensive description of clients served by both Harbor Area Adult Day Care Center and either Woods Guest Home or Autumn Cottage in 1985 is presented below.

Data on Persons in a 24 Hour Continuum of Day Care/Board and Care

The data presented in this section are based on the 16 clients who resided in Woods Guest Home and Autumn Cottage during 1985. In addition, another 18 persons from 7 other board and care homes attended the center during the year, some for relatively brief periods. The relationships between the day center and these homes is much less developed than with Autumn Cottage and Woods Guest Home, however, a significant amount of behavioral and nursing consultation were provided to 3 of the homes.

Information on mental status, and activities of daily living at time of admission to either day care or board and care and also at the current time or at discharge are presented along with age, sex, cost of care for both settings, length of stay for all 16 persons. In addition more detailed case histories on 4 persons whose care raised several issues which are significant in understanding the benefits and limits of this system. Mental status was evaluated by the Short Portable Mental Status Questionnaire (Pfeiffer, 1975) and activities of daily living were assessed by an 8 item scale with 5 possible points per item.

Table 2 - Data on Clients Attending Board and Care and Day Care in 1985

Name	Sex	Age	Mental Status Admission/Present	Activities of Daily Living Admission/Present	Date of Admission to Board and Care	Date of Admission to Day Care	Length of Stay in Either or Both Day Care & Board & Care
WOODS GUEST HOME							
L.B.	F	74	1/0	20/32	3/83	9/82	55 mo.
H.H.	F	91	1/1	20/32	11/82	4/83	39 mo.
L.M.	F	83	1/1	16/22	11/84	11/82	39 mo.
M.S.	F	77	2/2	17/21	6/84	6/84	20 mo.
M.M.	F	77	1/1	20/20	5/85	5/85	10 mo.
G.D.	F	74	3/3	20/20	11/85	11/85	4 mo.
A.B.	F	61	0/0	20/29	6/85	2/83	36 mo.
AUTUMN COTTAGE							
E.M.	F	82	1/1	18/33	11/82	4/84	39 mo.
H.M.	M	81	1/0	24/31	8/83	5/83	33 mo.
L.T.	F	85	7/7	17/17	1/85	1/85	13 mo.
H.P.	F	80	0/0	18/23	10/84	6/84	6.2 mo.
A.M.	M	86	3/3	24/21	7/85	4/85	10 mo.
C.C.	F	92	4/4	20/20	1/85	1/85	13 mo.
F.H.	F	88	1/0	16/40	1/84	7/81	52 mo.
L.W.	F.	78	1/1	22/20	4/85	4/84	22 mo.
F.B.	F	89	0/0	24/33	8/83	2/84	17 mo.

Most of the clients were women, the day center population is about one-third men. At Autumn Cottage the group is relatively old ($\bar{x}$ = 85 years of age), and at the Woods Guest Home the group is relatively young ($\bar{x}$ = 77) compared to a nursing home population. Cognitive impairment was moderate to severe on admission at both settings and continued so to date with one exception. The exception, Mrs. L.T., an 85 year old retired school teacher, suffered from a late onset paranoid psychosis. Mrs. L.T., who has no living family, was the 2nd grade school teacher of Dr. Sands and this seems to have facilitated positive adjustment to her current situation. Performance of activities of daily living has declined in most of the cases, with a direct positive relationshp between length of stay/duration of illness and the amount of decline. In 2 cases there was some improvement, in all cases save one there was maintenance of some abilities even up to 3-4 years from admission.

Data on the cost of caring for this group are presented on the following page in Table 3.

Cost of Providing Day Care/Board and Care to a Group of 16 Persons
With Alzheimer's Disease or a Related Disorder in 1985

WOODS GUEST HOME			HARBOR AREA ADULT DAY CARE		
Client	Number of Months	Per Year Board and Care	Day Care	Total	Per Month
L.B.	12	$ 13,000	3,306	16,306	$ 1,359
H.H.	12	10,400	2,948	13,348	1,112
L.M.	12	10,400	2,989	13,389	1,116
M.S.	12	10,400	3,323	13,723	1,143
M.M.	8	10,500	2,228	12,728	1,591
G.D.	2	2,500	713	3,213	1,607
A.B.	9	8,100	4,310	12,410	1,379
AUTUMN COTTAGE			HARBOR AREA ADULT DAY CARE		
E.M.	12	$ 23,118	2,571	25,689	$ 2,141
H.M.	12	20,626	5,662	26,288	2,191
L.T.	12	22,291	2,129	24,420	2,035
H.P.	6-1/4	10,937	1,842	12,779	2,045
A.M.	6	9,878	4,058	13,936	2,323
C.C.	6-1/2	11,046	713	11,759	1,809
F.H.	6	9,419	1,038	10,457	1,743
L.W.	6	9,123	3,215	12,338	2,056
F.B.	4	7,053	340	7,393	1,848

There are large and significant differences in average monthly costs between Autumn Cottage ($2,021) and Woods Guest Home ($1,330). Both homes are well under the average monthly nursing home cost in our area of $2,400. There are 2 primary factors that contribute to the differences in cost. One is capitalization, Woods Guest Home has been operational for 8 years and is wholly owned, Autumn Cottage has been operational for 3 years and carries a mortgage in excess of $150,000. The residents of Autumn Cottage are older, physically more infirm and require the care of a registered nurse which is available there.

The following case histories are selected to give some sense of the types of needs that bring persons to board and care/day care.

Mrs. H.P.

Mrs. H.P., an 80 year old woman entered the formal care system subsequent to the death of her husband. She had been suffering from Alzheimer's disease for 2-3 years prior to his death. Mr. P. was concerned that his wife would be a burden to others and in the 2 weeks immediately prior to his death, gave an overdose of pills, including pain killers, which were prescribed for him.

Mrs. P. was unconscious for several hours but recovered in the hospital, her condition was markedly worse. In addition to profound disorientation to time, place, person and situation she exhibited chronic agitation expressed as a need to return home to care for her husband, along with moderate agression when prevented from leaving her immediate situation. Initially she was placed in a large residential care facility, this situation failed almost immediately. From there she was moved to a board and care home and entered day care. After one month in the board and care she was moved to Autumn Cottage and continued in the day center. The agitation persisted with brief periods, an hour or two in duration, during which Mrs. P. seemed to enjoy living at Autumn Cottage and the activities at the day center.

Attempts were made to alleviate Mrs. P.'s agitation through the trials of haldol, mellaril, xanax, navane and inderal, all of which gave some relief for 2-7 days followed by a worsening of the problem. After 6 months at Autumn Cottage Mrs. P. was discharged to a locked nursing home where the problem persists but is tolerable.

Mr. A.M.

Mr. A.M., an 86 year old retired attorney, came to day care while living at home with a live in attendant. An attendant became necessary subsequent to his wifes' death in 1983. Mr. M.'s daughter reports a slowly progressive worsening of cognitive functioning over a 17 year period. Mr. M.'s condition was diagnosed as Alzheimer's disease in 1984. Mr. M.'s daughter and son-in-law participated actively in Mr. M.'s care and decided to place him in Autumn Cottage due to the difficulty involved in obtaining and maintaining adequate live in help. Mr. M. is disoriented to time and place, but maintains an awareness of persons and relationships and has some insight as to the situation he is in both at Autumn Cottage and at the day center. Mr. M. has improved in his ability to carry out activities of daily living, particularly with regard to incontinence. Although he will occasionally begin to walk away from the day center, he is perfectly happy to return when reminded that he has a ride coming. He participates in activities and enjoys the companionship of the other residents at Autumn Cottage.

Mrs. F.H.

Mrs. F.H., an 88 year old woman lived for many years alone subsequent to her husbands' death. In 1978 she experienced a sudden onset of a headache which she described as located just under the scalp in the middle of the right side of her head. She began to develop a loss of cognitive ability shortly after marked by difficulties with getting lost. For the next 3 years she lived with the younger of her 2 daughters in Pasadena. In 1981 she moved to live with her other daughter and at the same time began attending the day care center. Shortly after beginning the center Mrs. H.'s condition was diagnosed as a vascular dementia. Her most marked symptoms were an inability to learn her way around the center and delusions which stemmed from confusing the contents of her dreams with her day time experience. After a year in this situation, caring for Mrs. H. became excessively burdensome for her daughter and son-in-law, both of whom worked full time. She was placed at the Woods Guest Home and she continued at the center. Mrs. H. suffered a small stroke after a year which affected her walking significantly, and her daughter, not expecting her to live long, took her home. She continued to attend the center for the next year and actually improved slightly.

At this point her daughter placed her in Autumn Cottage. She continued there for 16 months, during that time she appeared to suffer several small strokes, and finally had to be discharged because she was totally non-ambulatory. Mrs. H. lived 2 weeks in a nursing home, 2 weeks in a board and care home which was licensed for non-ambulatory persons. At that time Mrs. H.'s grandaughter took her back to her daughters home and she died the same day.

Mrs. L.B.

Mrs. L.B. is a 74 year old retired interior decorator. Mrs. B. lived at home with her husband in Wisconsin until his death in 1983. At the funeral her son, who lived in California was surprised to discover that her thinking ability was severly impaired. Through talking to family, friends and neighbors, he was able to discover that symptoms of dementia had been notable and progressive for at least 6 years. Mrs. B.'s son brought her back to California with him. Mrs. B.'s condition was diagnosed as Pick's disease. On admission she was disoriented as to time, somewhat oriented as to place and situation and oriented as to person.

Although some motor impairment was noted, she was still an active and fairly graceful dancer, and although she had marked word finding difficulties, she sought out and enjoyed conversation. She was moderately independent in activities of daily living.

Mrs. B. began day care almost immediately upon moving to California and moved to the Woods Guest Home a month later where she continues at present. Over the last 3 years Mrs. B.'s condition has steadily worsened to the point where she walks with a rigid shuffling gait, is mute and is almost totally dependent in all activities of daily living. Nevertheless, she seems to recognize her caregivers, smiles readily and although verbally non-responsive, still seems to enjoy conversation.

Summary/Future Goals

South Coast Institute for Applied Gerontology has developed a 24 hour care system for persons with Alzheimer's and related disorders in conjunction with Woods Guest Home and Autumn Cottage, and in cooperation with caregiving families. At any given time the system sustains about 65 persons in familial caregiving settings and 15 persons in board and care homes. In addition, 24 hour respite care is available in Autumn Cottage and 4-6 families make use of this service for periods varying between 2 days and 2 weeks. Skilled nursing care is provided in the day center and the centers' nurse is available to the board and care homes and families as a consultant.

Our plan is to expand this system to provide service to 300 persons with Alzheimer's or related disorders in a close approximation of the "nursing home without walls" developed by On Lok in San Francisco, (Annual Report, 1984-1985). Their program has been developed primarily for persons needing long term care due to all other causes then dementing illnesses such as Alzheimer's disease. If we could expand our program, we feel we could provide a higher quality of service at comparable or lesser cost than nursing homes.

At present we operate adult day care centers, but we also provide 24 hour care either for respite or as a stable placement in conjunction with board and care homes. We also provide behavioral and nursing consultation to the board and care homes and to families. We also provide back up services to several private physicians. In order to compete for Medicare/ Medical payments we will need to consolidate services.

A logical expansion is to establish a medical clinic in the centers. This should include minimally a nursing service and the services of a neurologist for assessment and treatment of behavioral/emotional problems related to dementing illnesses. It may be an advantage to provide additional physician services as well. We have an application for a clinic license pending at this time. This takes advantage of the positive institutional aspects of adult day care, e.g. Many people can be seen in the same space without a need for rigid scheduling and where there is an extensive amount of observation by trained staff.

We need to have a home health care component to provide consultation and care in the board and care homes and to caregiving families.

The staff of the home health care group could also serve as the professional staff for the adult day care center.

To serve 300 patients we would need an additional 90 day care slots. At present we have 35 at Harbor Adult Day Care Center and 25 at Huntington Valley Adult Day Care Center. This would require opening 3 additional centers.

We would also need to either open or develop working relationships with another 7-9 board and care homes. At present we have close working relationships with 2 homes.

To summarize the entire project would consist of an intergrated care system consisting of:

a. 5 adult day care centers with a total daily capacity of 150 patients and an overall capacity for 300 patients.

b. A medical clinic which would operate in each center 1/2 day per week for assessment and care of behavioral/emotional problems related to dementia and for basic nursing care.

c. A home health care service, the professional staff, nurses and social worker, will also serve the adult day care centers.

d. 10-12 board and care homes, some of these could be operated by South Coast Institute for Applied Gerontology or all could be related as affiliates. This would give us a total capacity of 60-72 beds with some beds available for respite care. Ideally at least one of these homes could be operated as a hospice.

Current estimates indicate that there are at least 1-1/2 million persons in nursing homes and that at least half of these patients are there due to a dementing illness such as Alzheimer's disease. It is likely that some percentage of these patients with Alzheimer's type diseases would be best treated in locked facilities, but this group would probably not exceed 20% of all demented nursing home patients (150,000). We feel that the majority of the remaining 600,000 patients could have been better cared for in a community based system.

Of course most of the patients who entered nursing homes while ambulatory are no longer able to walk and could not be transferred to a system depends on maintaining the patients independence. Nevertheless, it is important to increase the opportunity to seek this form of care by changing policy so that alternatives are available to chronically ill older Americans (Subcommittee on Long Term Care of the Special Committee on Aging, United States Senate, 1974.)

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Institutional Approaches To The Care of Individuals With Dementia: Report of a National Facility Survey and The Hebrew Home for the Aged at Riverdale, as a Case Study

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I. INTRODUCTION

The provision of competent, compassionate and cost-effective care to individuals with dementing illnesses, and their families, has become a critical concern of Federal, State and local governments, the formal and informal care networks, service advocates and consumers (HHS, 1984, New York Academy of Medicine, 1985, New York City Department of Mental Health, Mental Retardation and Alcoholism, 1985). The 1985 initiative by Congress to the Office of Technology Assessment "to analyze the public policy implications of the large number of people who are affected... "represents an important step toward a cohesive, national, long-term care policy in this regard.

In contrast to this recent increased interest in care for the individual with dementia, it should be noted that institutional, long-term care facilities have always cared for individuals with serious cognitive impairments - whether it was under the rubric of "senility", "hardening of the cerebral arteries", "organic brain or mental syndrome", or more recently "dementia - probably of the Alzheimer's type." What has changed is not the existence of a population with dementing illnesses but, rather, their proportion within the total number of institutionalized aged has increased significantly.

Estimates of the presence of cognitive impairment among nursing home residents range from thirty to eighty percent. While these statistics vary with definition, four surveys are germane, beginning with the *1977 National Nursing Home Survey* that found almost 60% of nursing home residents to have chronic brain syndrome or senility without psychosis (National Center for Health Statistics, 1979). Similarly, an assessment of a Washington, D.C. nursing home

(Rovner & Rabins, 1985) indicated that 70 to 80% of the residents had some form of cognitive disorder - of which Alzheimer's disease and multi-infarct dementia were the most common cause. These results are consistent with the 1984 survey of 42 skilled nursing facilities in upstate New York confirming that 64% of the population had moderate to severe behavioral problems ranging from impaired judgement to danger to oneself and others (Zimmer, et. al., 1984). Katzman (1985), in a recent evaluation of nursing home admissions (also) in New York State, noted that seventy-five percent had some form of dementia upon admission; these were not symptoms which developed following prolonged nursing home residency.

Perhaps the primary reason that nursing homes have become the major source of institutional care for the elderly mentally impaired population is the concomitant de-institutionalization of the State mental hospital system population and the quadrupling of nursing home beds in the United States over the past twenty years (U.S. National Center for Health Statistics, 1979, Johnson & Grant, 1985, Brody et. al., 1984). Changes in contemporary society from the demographic as well as nuclear family perspective have also increased the role of the nursing home. With the dramatic increase in the number of individuals 85+ years, was a decline in the availability of informal supports as a function of changes in the woman's role toward employment, fewer children, greater geographic diversity,and an increased divorce rate (Grossman, et. al., 1986, Brodv, et. al., 1984, Johnson & Grant, 1985).

It is estimated that one million people over age 65 suffer from severe dementia with an additional 2 to 3 million mildly affected (Ringler, 1984). ← Not in citations
Inasmuch as the prevalence rates of SDAT increase from approximately 2% in

those age 65-70 to 22% in those 80 years and over (Brody, et. al. 1984) the rapid growth of the old-old age cohort makes the issue of appropriate and effective institutional response critical to the needs of the demented population.

The notion of homogeneous versus heterogeneous placement of individuals with dementia in nursing homes has been intellectually debated in the literature. It has been suggested that patients with varying levels of clinical need should be integrated on the same nursing unit, i.e., "main-streaming" (Ablowitz, 1983). It is further postulated that such integration will result in a beneficial impact for all patients on the integrated unit. Those with lower levels of need may enjoy or benefit from helping the more impaired patients. Those patients who are more impaired may benefit from the companionship of a patient who functions at a higher cognitive level. Bergman (1983) specifically suggests that residents with different abilities compensate for fellow patients' lack of ability, seemingly without peer or staff pressure. Gurland (1985) further suggests that segregation is a reaction to staff and family who find disruptive behavior disconcerting.

In contrast, Bowker (1982) reported that mixing of patients with different levels of functioning may result in a strong sense of dehumanization. Specifically, such integration of patients may have a demoralizing impact upon those who need to demonstrate their own mental competency (Smithers, 1977). Wiltzius (et. al. 1981) noted negative changes in mental and emotional status in competent residents whose roommates were confused. Further, the severely impaired patient's response to a "typical" skilled nursing unit may be explosive or result in withdrawal from a setting which is too demanding. In contrast, an oriented, rational individual may find the supportive, environmentally modified unit confining, too circumscribed and devoid of interest (Goldfarb, 1973).

An experiment on the effects of segregating and integrating the mentally impaired (Kahana, et. al., 1970) was inconclusive with regard to the patient population, but did suggest benefits, for staff, of related stimulation and attitude training. Hiatt (1985) also supports the notion of patient placement by functional level as a means to more effectively and efficiently pool resources.

Mace (1985) simply concludes that special units have shown that patients can benefit from a safe environment and planned activities.

Regardless of its philosophy or approach to patient placement, the long-term care facility has an important function within the continuum of services for persons with dementing illnesses. Haycox (1980) suggests that when the patient can no longer recognize the caregiver, institutional placement becomes appropriate. Clearly, the role and importance of the nursing home is increased when there are limited informal care networks (Oriol, 1985). Interestingly, it has been suggested that the nursing home is, in fact, the most appropriate and effective option for care of the moderately to severely demented individual (Brody, et. al., 1984). Yet, as the (1984) Report of The (HHS) Secretary's Task Force on Alzheimer's Disease emphasized, increased efforts are required to evaluate the:

> "socio-environmental and organizational characteristics of long-term settings (i.e.size, type of institution, staff to patient ratios) which effect the functioning and well-being of Alzheimer's disease patients."

Similarly, a recent survey of American Association of Homes for the Aging facilities also indicated a desire for information regarding staffing, environment and design for programs for this population cohort (Webb, 1985).

This report documents long-term care facility response in the care of patients with dementia from two perspectives. The first component provides an overview of the approaches taken by facilities nationally that have identified themselves as providing "special programs for individuals with dementia." Part 3 utilizes the Hebrew Home for the Aged at Riverdale as a case example of a large, voluntary, long-term care facility's special care unit (SCU) approach.

It should be noted, at the outset, that in the context of this report, dementia refers to the DSM-III categories of: primary degenerative dementia, senile onset; primary degenerative dementia, pre-senile onset, and; multi-infarct dementia, each including the sub-types of delirium, delusions, depression, and uncomplicated (American Psychiatric Association, 1980).

II. NATIONAL FACILITY SURVEY

With the support of the Brookdale Foundation, and in the context of The Hebrew Home for the Aged at Riverdale's (HHAR) own institutional planning, an in-depth mail survey of facilities (see Appendices A and B) identified as having special programs for individuals with Alzheimer's disease and other dementias was conducted. These 48 facilities were identified as a result of earlier American Association of Homes for the Aging and National Association of Jewish Homes for the Aged surveys, a computerized literature review, grass-roots research and collegial correspondence. Of these, thirty-eight (80%) responded to the more in-depth questionnaire as detailed in this paper. These facilities represent the diversity of geographic locations, religious and secular affiliations, and agency size. Thirty-three (86%) are voluntary, non-profits; 5 (14%) are proprietary facilities. While more than 10,250 beds are represented by these facilities, this information is presented as descriptive with the caveat that these are self-selected facilities and programs.

Development of Special Care Units

An indication of the provision of special programs does not defacto indicate the existence of special care units (SCUs) for individuals with dementia. Of the thirty-eight facilities, twenty-five (66%) have developed such designated units. (See Table 1)

The majority of SCUs are at the SNF level of care or within facilities with only one level of care. The number of beds allocated to special care units ranges from 8 beds to 200 beds and 6% to 51% of institutional bed complement. Further, the average designation is 12% of bed complement and 1.5 such units in the facility. The contrast between the 12% complement designation (for patients with dementia) and the probable number of patients with dementia (exceeding 50%) is noteworthy.

The establishment of such SCUs is not a new phenomena within practice realms; the "average" unit having been established 5.4 years ago. While the "age" of the oldest unit exceeds 24 years, both OTA and HHAR learn of new SCUs

Table 1

Organization of Patients with Dementing Illnesses

(N=38)

Approach	Number	%
Discrete, planned & designated Special Care Unit	25	63
Progressive, functional placement without SCU designation	5	14
Considering SCU development; currently have special activities	5	14
Cluster approach on one unit	1	3
Closed a SCU in favor of heterogeneous placement	1	3
Special activities, are not considering a SCU	1	3

seemingly on a daily basis. SCU development is almost equally divided between new construction and conversion of traditional ICF/SNF units.

It should be noted that one-third of the respondents indicated increased costs associated with SCU programs. Private rates vary from $40 to $120 per day.

Reported Objectives of a Special or Designated Unit

Special care unit objectives provide an operational framework, and context for further decision-making and program development. Program objectives or goals articulated most frequently by those facilities surveyed, are summarized in Table 2.

In addition, some facilities specifically indicate clinical goals including: the elimination of restraints; the elimination of diapers and catheters for the incontinent patient, and; the minimization of psychotropic drugs.

The determination of objectives, is usually followed by the development of admission and discharge criteria, including age, behaviorial and functional criteria, and a decision regarding priority admissions (i.e. transfers) for in-house residents. It should be noted that only 5 of the facilities responding waive their 60/65 year minimum age requirement and 51% give priority for admission to the SCU to the current facility patient population (via transfers).

Table 2

Reported Special Unit Objectives

1. To provide a safe, and secure environment which is supportive from both a nursing as well as socialization perspective.

2. To reduce feelings of anxiety and confusion through both environmental and communication supports.

3. To "rehabilitate" or maintain the patient at their optimal level of physical and cognitive function.

4. To provide care to the patient in a holistic manner.

5. To recognize that these patients have come to facilities to live, rather than merely exist, and provide experiences and activities which will add to the quality of their lives.

6. To recognize that patients are autonomous human beings who can expect that their special needs and those of their families will be met with sensitivity and appropriateness.

7. To provide each patient with opportunities to succeed which will build their sense of self esteem, dignity and hope.

8. To improve the quality of life/living environment of mentally intact patients, residing on traditional SNF units.

9. To support the caretakers (staff, families and significant others) through understanding, training, education, and the minimization of stress (AAHA, 1985; Weissman, 1984; Peppard, 1984; Clark, 1982; and Weiner, 1985).

From the survey, twenty-six facilities indicated that patients were placed according to their level of cognitive/behavioral function. Of these, two facilities indicated that this was but one component of a more comprehensive system of patient placement based upon functional assessment. These facilities did not create an Alzheimer's Special Care Unit.

Table 3 categoriezes the approach within thirty-one facilities with operational (or planned) SCUs or clusters. Of the five facilities identifying diagnosis as a criteria, it is not an automatic criteria for placement, but rather linked to other behavioral and functional measures. Only four report use of validated assessment tools including the MSQ.

Of these facilities, six identified their programs as serving individuals with "mild to moderate" dementia without being part of a larger, progressive institutional system of placement. It should be noted that there was no relationship between this definition and the level (i.e. SNF or ICF) of care.

Unit Designation

Approximately seventy percent of the facilities utilize their existing institutional nomenclature in referring to these units, for example "E" Floor, Barnhard Unit. In addition,

°Two facilities call their special units - "Life Enrichment Units".

°Two facilities do refer to these floors as "Alzheimer's Unit" or "Alzheimer's Division".

Table 3

Overview - Special Care Unit Role Within The Long-Term Care Facility

(N=31)

Definition		Number of Facilities
"Short-term" placement, discharged to traditional SNF when:		24
° The patient is not able to respond to and benefit from the structured approach	11	
° Physical care needs increased	8	
° The patient becomes non-ambulatory	8	
° Behavior becomes extremely disruptive	4	
Multiple units, progressive intra-unit placement		3
Long-term or permanent placement		4

Note: If patient was misdiagnosed, or improves, transfer to traditional SNF is effected, regardless of other admission/discharge criteria.

°One facility had a staff contest to name their unit and now utilize the acronym "MIND" which means "maintaining independence in neuro-circulatory disorders" (Fishkill Health Related Center, Beacon, New York).

Environment

Fifth-eight percent of the facilities with special care units developed these through conversion from more traditional ICF or SNF units. Regardless of the SCU/cluster or special program approach, there was, a consensus about the importance of the environment for safety and security, orientation, organization and structure, and the minimization of agitation and other behavior problems as detailed in Table 4.

In addition:

°Two facilities utilize private rooms only.

°Two facilities are designed around a cluster (6-8) of patient rooms that open onto a communal day area.

°One facility indicates the addition of considerable texture for noise control and sensory stimulation.

The value of an SCU on the ground floor with the possibility of an adjacent and secure "wandering garden" was specifically reported as beneficial to patients, family and staff (the latter for reduction of burnout).

Table 4

Environmental Modifications/Supports *

(N=33)

	Number	Percent 1.
Increased Security/Visual Access	29	(87%)
° Alarming, coding, securing exits	28	(84%)
° Modification of nurse's station	5	(15%)
° Coding, securing, camouflaging elevators	5	(15%)
° Securing patio/garden areas	10	(30%)
° Use of wide angle mirrors	3	(9%)
° T.V. monitors	1	(3%)
2. Increased Orientation	15	(45%)
° R O boards, large calendars, daily schedules	12	(36%)
° Color coding - corridors, furniture, etc.	7	(21%)
° Large letter/number/object room identification	8	(24%)
° Directional signs	1	(3%)
° Remove poisonous plants, electric wires	1	(3%)
3. Modification of Communal Spaces	10	(30%)
° Increased square footage	7	(21%)
° Garden, walkway created	5	(15%)
° Space modified to provide smaller areas for small group activities	3	(9%)
4. Noise Control	9	(27%)
° Carpet tiles	5	(15%)
° Elimination of intercom or PA system	2	(6%)

*Note: Many facilities utilize more than one technique to secure the environment, etc.

Staffing

Twenty-six skilled nursing facilities provided adequate information for staffing comparisons as noted in Table 5. Within these, facility size ranged from 120-784 beds, the number of "dementia unit beds" from 8-200. Existing staffing patterns were calculated and adjusted to a forty-bed SNF unit for ease of comparison.

It should be noted that staffing intensity was related to reported severity of patient condition, within the framework of SCU goals.

Indications of social work or recreational staff allocations were not consistent. However, where these were included, there was a range from .3 FTE to 1 FTE for both social work and activities staff, based on that illustrative 40-bed unit.

There are several approaches to staffing that merit note:

1. Activity workers assigned to a 10 a.m. to 6 p.m. shift, more reflective of available program hours.

2. Social work and activity workers' offices located on the special care units.

3. The use of part-time feeders, assistants or nurse's aide staff on the evening shift for feeding, and assistance at bedtime.

4. The use of "lounge aides" in addition to nursing assistants to supervise patients within lounge areas.

Table 5

Comparison of SCU Staffing Within SNF Facilities [1]

(N=25)

SNF Facility	Nurses RN+LPN			Aides		
	Day	Evening	Night	Day	Evening	Night
1.	4.7	4.	4.	8.	8.	4.
2.	3.9	1.3	1.3	5.2	5.2	2.6
3.	3.9	1.3	0	3.9	2.6	1.3
4.	3.5	-[2]	-	9.8	-	-
5.	3.2	1.6	1.6	6.8	4.	1.6
6.	3.	1.5	.75	4.5	3.	3.
7.	3.	1.4	1.4	4.9	4.9	3.5
8.	2.7	1.8	.9	5.4	4.5	2.7
9.	2.6	1.9	1.3	5.7	4.3	2.6
10.	2.6	1.3	1.3	5.2	3.9	2.5
11.	2.5	1.7	.8	6.6	3.3	1.6
12.	2.4	1.6	1.6	5.7	3.2	1.6
13.	2.4	2.4	1.6	6.4	4.8	4.8
14.	2.2	1.5	.7	4.2	4.	3.
15.	2.1	1.	1.	5.2	4.2	3.1
16.	1.8	1.8	1.8	7.4	5.4	3.6
17.	1.8	1.2	.6	4.8	4.2	2.4
18.	1.6	1.6	.8	7.	5.2	3.5
19.	1.5	.5	.5	6.0	6.0	5.0
20.	1.4	1.4	.3.	5.2	5.2	1.3
21.	1.3	-	-	6.5	6.5	4.3
22.	1.2	1.	0	5.	5.	5.
23.	1.2	1.2	.9	3.5	3.5	2.7
24.	1.	1.	1.	5-6	3-4	1
25.	-	-	-	6.5	4.5	2.5
Average by Category	2.4	1.5	1.0	5.8	4.5	2.9
Median	2.4	1.4	.9	5.6	4.3	2.7

Notes: 1. Based upon extrapolation to a forty bed SNF unit
2. "-" reflects omission in data.

5. The modification of traditional specific discipline or departmental responsibilities for tasks and activities. For example:

- °In three facilities, nurse's aides conduct reality orientation, remotivation, grooming and activity programs. Two other facilities have plans to utilize this approach.
- ° Within three facilities, nurse's aide assignments are based on patient functional levels, allowing staff to conduct small group programs for persons at similar levels.

6. In twenty facilities (15 non-profit and 5 proprietary) there are "coordinators" for their special care unit. Their time commitment ranges from .5 FTE to full time with no relationship between either their existence, time allocation, or the number of designated special care beds. Most typically, this individual is a registered nurse (55%) or social worker (15%). In three facilities (15%) the responsibility is shared between nursing and social work. These individuals usually have the title of "Clinical Coordinator" with responsibility for program innovation, staff education, problem solving, and within, the proprietary facilities, program marketing. In one case, the coordinator is also responsible for actual programming on the unit.

Training

Twenty-eight of the facilities completed information regarding the type and level of training, education and staff supports provided within the context of "special programs" as detailed in Table 6. Facilities with regular staff and

Table 6

Staff Supports and Education

(N=28)

Response:	Number	Percent
1. Staff/team meetings (most usually weekly) distinct from actual care planning sessions	21	(75%)
2. Continued inservice	21	(75%)
3. Training prior to the development of the unit; and/or special training for new staff who will work on the special care unit	17	(60%)
4. Use of psychogeriatric hospital teams or other consultants for clinical input, rounds and education	4	(14%)
5. Team rounds	1	(3%)

team meetings underscored their importance from the perspectives of "ventilation" and the discussion of specific clinical issues. Initial training ranged from four to sixty hours addressing the clinical course of dementia, its cause, changes in behavior, communication patterns, and useful strategies in relationships with patients and family members.

The survey also indicated a clear understanding and integration of the importance of support for family members, as 81% of the facilities reported use of family group programs for emotional support and education.

Activities

Facility approaches to activities on dementia units vary from the highly structured, purposeful approach akin to The Burke Rehabilitation Model (Pannela, 1984) reported within five facilities, to a more flexible adaptation of institutional programs and weekly variety.

Table 7 provides an overview of activities utilized in rank order.

Research/Community Services

Sixteen (34%) of the facilities noted the existence of research activities. Of these slightly more than half relate to the impact of the SCU.

Table 7

Activities Utilized Most Frequentlv Within Special Programs for Dementia Patients

(in rank order)

(N=30)

Program	Number	Percent
Physical exercise (walks, adaptive sports, dance exercise, movement, wheelchair exercise)	22	(73%)
Music (singing, active/passive listening, "Mozart and wine")	19	(63%)
Cognitive stimulation (e.g. word games, communication, reminiscence)	11	(36%)
Crafts	9	(30%)
Reality orientation, remotivation	9	(30%)
Sensory stimulation, awareness (conducted by Occupational Therapy Department)	8	(26%)
Grooming, basic skills classes	8	(26%)
Cooking	7	(23%)
Bingo	5	(16%)
Ice cream and cocktail parties	5	(16%)
Horticulture	2	(6%)
Pet Therapy	2	(6%)
Sheltered workshop	1	(5%)

Thirteen (34%) of the facilities responding noted extension of services to community-residing elders. Most "typical" was the provision of adult day care services (8), outreach (3), and information and referral (2).

While neither this descriptive survey nor other reports within the literature draw conclusions regarding an ideal or model approach to caring for the institutionalized dementia patient, the diversity of organizational and programmatic options are of interest and value. The survey suggests that the SCU approach is viewed as an increasingly viable and popular approach within the nursing home sector. Clearly, research is required to evaluate its differential impact upon patients (both mentally intact and demented); staff, families, volunteers as well as the institution itself. Further, while the survey indicates a sharp contrast between the "typical" 12% bed designation for SCUs and the average 50% facility incidence of patients with dementia, we remain unsure of the "appropriate" institutional balance.

It is clear that SCU and/or special program development requires both substantive as well as process steps to succeed. Yet, until "success" is defined according to standards or outcomes of care, we must rely on intuitive clinical judgements to determine what is effective and/or valuable. Yet this descriptive material is useful in outlining existing approaches to care of the patient with dementia. Its lacking in depth, is related to the current state of the art, i.e. we do not yet know what goals are realistic, appropriate, valid, achievable nor which approaches (including programmatic, staffing, environment, family supports, etc.) are most successful in reaching these goals.

The HHAR, recognizing this paucity of knowledge, utilized its clinical expertise and administrative perspective to develop its Special Care Unit approach. Part 3 describes the process, substance, and outcome of this endeavor.

III. THE HEBREW HOME FOR THE AGED AT RIVERDALE

Historical Perspective

The Hebrew Home for the Aged at Riverdale, (HHAR) incorporated in 1917, is a voluntary, non-profit, non-sectarian, long-term, residential health care facility, in the Bronx, New York. Its origins, 68 years ago, were in a Harlem brownstone which functioned as an overnight shelter for 39 older adults. To accommodate the increasing need for shelter and care of older adults in the New York metropolitan area, the 18 3/4 acre campus on the Hudson River where the main campus is presently located, was purchased in 1948.

In the last four decades, the Home's planned institutional growth resulted in construction of three RHCF pavilions (the Infirmary building - 1958; the Goldfine building - 1965, and; the Palisade Nursing Home - 1975); renovation of the original main campus building (Stolz Pavilion - 1979); construction of a HUD/202, 137 unit apartment facility (River House West - 1980), and; purchase of a nearby 167-bed SNF to become a satellite facility (Fairfield Division - 1980).

In early 1985 ground was broken for the Henry Kaufmann Pavilion/Alzheimer's Comprehensive Care Center, which will replace the bed capacity of the Infirmary

Building as well as include an additional 49 licensed but presently non-operational HRF/ICF beds. The total number of aged individuals residing within these facilities exceeds 1100 persons.

A planning grant from the Brookdale Foundation to "Develop a Continuum of Care for Individuals With Dementia and Their Families" complemented facility construction eleemosynary support and provided the resources to complete the national facility survey detailed in Part Two of this report.

In addition, HHAR provides more than 330 "Meals on Wheels" daily and is anticipating approval in January, 1986 to open an adult day care program in which individuals with dementing illnesses will be served. Research and training activities complement core patient care services.

Special Care Unit Development

HHAR has had a long tradition of program and training innovation with regard to caring for a population with dementia, beginning with the establishment, in 1961, of an NIMH-supported workshop for the cognitively impaired. The remarkable nature of the 1973 lecture series by Dr. Alvin Goldfarb on working with the confused elderly was underscored by its fourth printing as a Monograph in 1982 (also with NIMH funding). Appendix C includes the Monograph resulting from the 1983 regional professional symposium sponsored by HHAR on "Alzheimer's disease and Related Disorders."

In 1983, HHAR had six ICF/HRF living areas and ten SNF units. Included within these SNF units were two "intensive units" (B and C floors) developed some 25 years ago, as "infirmary units" for patients identified as management concerns, and/or those acutely ill patients requiring very substantial nursing care. The primary difference between these and the other SNF units was the higher level of nursing staffing. In more recent years these units were used for permanent placement of patients who were "difficult to manage" from the medical and/or behavioral perspective.

A long waiting list for transfer and admission to these units as well as the expressed concern of alert patients and institutional staff about the patient mix on the other eight SNF units prompted an evaluation of the patient profile and institutional need (Grossman, et. al., 1986).

With the support of the Gerontological Society of America post-doctoral fellowship program in 1983, HHAR was able to re-evaluate its institutional preference (and actualization thereof) of homogeneous placement of patients with irreversible dementing illnesses. A three-pronged approach solicited input from patients and staff and documented changes in the Home's patient profile.

Forty percent of the clinical care staff, including social workers, doctors, nurses, aides and physical and occupational therapists on the ten SNF units were randomly selected and asked to respond to a questionnaire addressing two basic issues:

1. Could better care be provided to the patients if the units were segregated by behavior and function?
2. Would the patients be more comfortable if they were so segregated?

? was this the terminology?

As Table 8 indicates, 76% of the clinical care staff felt that they could perform a better job in providing more direct service if the units were segregated. Eighty-three percent of the clinical care staff felt that patients would feel more comfortable if they were segregated by level of care. In addition, in response to expressed concerns by HHAR's Resident Council, 48 (10%) of all SNF patients were randomly selected for interview. Of these individuals, only 24 could take part in the interview due to severe cognitive impairment. Those who were interviewed, however, were almost unanimous in stating their preference for homogeneity of placement. Only one of the 24 patients stated a preference for being on a unit where others had different clinical care needs (Salamon, 1983).

In addition to the patient and staff interviews, actual and perceived patient care needs were also assessed. This third component of the process included a retrospective analysis of DMS-1 scores*, for all HHAR's patients for 1978-1983. Additionally, a survey of patient care staff was performed to determine their perception of the extent of the "changed patient profile" at the Home (Salamon, 1983). This was followed by an assessment of functional levels of all patients using Katz's ADL Scale (Katz, et.al., 1963). This provided a measure of convergent validity and helped to determine current levels of need for special care, as a result of functional deterioration.

When presented with the documented changed needs of patients, the preferences of the more alert and oriented patients, as well as staff's perception of their ability to provide better care, the Administration of the

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*The New York State tool which measures appropriateness of nursing home placement and placement level as a condition of Medicaid reimbursement.

Table 8

Staff Responses to Questions Regarding Ability to Better Provide Care if Units were Segregated by Patient Functional Levels

SNF Unit	Better Care Could Be Provided	Patients Would Be More Comfortable
1	64%	88%
2	86%	100%
3	83%	67%
4	60%	60%
5	60%	80%
6	75%	75%
7	60%	80%
8	60%	80%
9	83%	80%
10	100%	100%
Overall	76%	83%

HHAR supported the initiative to develop a "SCU" for patients with dementia. A related goal of this initiative was to examine the effectiveness and viability of the model of care (to ultimately be developed on Goldfine-1 [GP-1]) with potential expansion onto the two already existing special units (i.e. B and C floors).

The development of this SCU required the concurrent operation of two planning processes. The first, a Task Force chaired by the facility's Associate Executive Director, was comprised of relevant Patient Care Department Directors (medicine, psychiatry, psychology, social services, nursing, therapeutic and recreational therapies) and two Assistant Administrators and was responsible for basic decision making and implementation regarding unit organization and therapeutic approach. A second group of direct care staff, whose efforts were coordinated by the Director of Social Services (also the designated Admission and Discharge Coordinator), was responsible for the identification of eligible patients and appropriate transfer protocols. It should be noted that this Task Force originally viewed as an ad hoc staff committee, has met periodically to re-evaluate approaches and discuss the pragmatic issues of implementing the GP-1-SCU therapeutic milieu onto B and C floors.

The initial planning process required approximately six months and resulted in a series of sequential decisions which defined the goals, framework and program focus and directed the actual implementation steps.

1. Admission criteria were developed to encompass a combination of behavioral and functional criteria as defined in Appendix D. Although the "model" program was to be developed and implemented first on GP-1, and subsequently on B and C Floors, admission criteria

for each of these three designated special care units were determined to be consistent with the exception of placement of individuals who wandered onto the more protected GP-1 and C floors. During this planning process, the Task Force determined that placement decisions would be "permanent", with the exception of those persons whose condition improved. This decision is currently being re-evaluated in light of the existing waiting list for placement on the SCU's and a small number of patients currently residing on the SCU's whose "ability to benefit from the developed structured therapeutic approach" has been significantly reduced. This decision is a difficult one especially as it requires value judgements regarding allocation of limited resources.

It should be noted that the Home does not have a minimum age requirement for either the SCU or any of the HRF/ICF/SNF units.

2. Philosophy - In developing this unit, the issues attendant to social components of care, dignity, respect, and maximization of potential, were articulated; Table 2 includes the framework defining HHAR's approach to caring for this population. Specific outcome objectives were not identified.

3. A milieu therapeutic approach (Scekais, 1985, Grossman, et. al., 1986) was defined in the context of HHAR to include the role of both the physical and programmatic environments. While there are very few models for the development of such units within traditional nursing homes (Benedict, 1983) literature does exist on making the nursing home environment more comfortable for patients (Hiatt, 1980).

Conceptually:

A. The physical environment should be active, not passive, in its ability to protect, orient and provide space for safe wandering.

B. Throughout the day, activities should be offered that are at appropriate physical and cognitive levels, stimulate all of the senses, offer both physical and intellectual exercise, build upon earlier adult interest, involve all therapeutic disciplines and allow for small group activities within specific levels of cognitive function. In addition, activities should be scheduled to support the natural, individual energy cycles and patterns. It should be noted that this definition reflected clinical judgements regarding competent sensitive programming, with the recognition that there is little research to support (or refute) these perspectives within the SCU context.

4. Staff supports , including education, case discussions and opportunities for ventilation were viewed as critical for SCU success.

5. Location - As a result of individual patient assessments, GP-1 was was determined to be the most appropriate unit for conversion; only 11 patients were determined ineligible for a SCU given their (higher) level of cognitive function. Patient transfers were affected to minimize location trauma for the patients, families and staff members (Borup, 1982, Grossman, et. al., 1986).

6. A geographic or unit-based family group program was already in existance on the unit, co-led by the unit social worker and head nurse, providing an ideal opportunity and setting to discuss the "SCU" approach to care. It was clear that this monthly family group meeting would continue to provide both emotional support and basic education.

7. Continued use of the geographic location name, i.e. GP-1, was deemed preferable to either "psychogeriatric" or a "Alzheimer's unit," to avoid stigmatization of the population from the family and staff perspectives.

Actual Implementation Steps

Environment

Environmental modifications on GP-1 were nominal in time and cost. This unit is 24,339 square feet, designed essentially as a square with a core, central nursing station. There are 12 double and 18 single rooms, consistent with New York State facility requirements. The congregate dining area is adjacent to but separated from a larger lounge area by glassed walls. Terraces, and one larger garden area, extend the communal spaces.

Initial environment changes related to security and orientation and included: alarming of the exits; color coding of doors and hallways; erecting double-view mirrors; lowering the height of the nurse's station; installation of addition terrace guard rails to prevent accidents; installation of additional reality orientation boards, and; development of large daily schedules of patient activities. Several weeks following the establishment of this Special Care Unit, family members, staff and patients worked together to personalize patient room doors with memorabilia or other items that would enhance individual orientation, e.g. barber pole (barber), a notebook (elementry school teacher), and G-cleft (pianist). This was consistent with the belief that orientation is important for individuals with irreversible organic impairments (Parker & Sommers, 1983).

Subsequently, a "wandering garden" was created in an outdoor area adjacent to the unit, secured and camouflaged by movable garden boxes (these also provided an opportunity for horticulture programs), and art hung in the corridors consistent with the color-code design. Consideration is now being given to the elimination of the P.A. system in the unit dining room (noise control), modification of the elevator to minimize and/or eliminate patient egress, installation of a canopy for shade in the garden area and installation of an air lock system to minimize air conditioning loss from the unit onto the garden area.

The Involvement of Families

In working closely with the families, the social workers built upon institutional philosophy and commitment to families as both partners in care and clients in need of social work intervention. Acknowledgement was given to the view that within institutional long-term care a move to a more intensive level of care is a crisis step for the family (Solomon, 1983). An existing Family Group on Goldfine-1, (the then designated SCU) co-led by the unit head nurse and social worker helped to ease the anxieties surrounding the transfer and re-location processes. Consistent with this approach, the plan to develop a SCU on Goldfine-1 was first introduced at a Family Group meeting. Representatives of administration, nursing and social services explained the goals of the SCU and the process of transfer. These monthly Family Group Meetings (on all SCUs) continue to be an important forum for education, support and problem solving.

Family acceptance of the Special Care Unit can be measured by the lack of resistance to transfer of patients to this unit, when indicated, and increased participation in the Family Group, unit activities, and planning for the care of their relatives. Current plans for increased family participation include joining patients for lunch/dinner on-the-unit, while simultaneously assisting in feeding.

Staff Meetings

Prior to the patient transfer process a series of staff meetings (nursing - all shifts) and community meetings (all patient care and support staff) on GP-1 were conducted to discuss unit goals, approaches and resultant staff concerns. With this introduction, daily 15 minute team meetings and twice monthly community meetings (day shift) were complemented by regular evening and night team meetings for the first year. At present, team meetings are conducted three times a week by the unit head nurse and Assistant Director of Social Work (there is currently a unit social worker vacancy).

Potential Improvements in the Planning Process

In retrospect, there were two ways in which the planning and implementation phase could have been improved. The first, is earlier involvement of the nurse's aides to obtain their insight into pragmatic caregiving problems and issues and also to simply improve the "process" of the actual planning. Secondly, despite the seriousness of the planning endeavor and clear administrative support, responsibility and authority for project implementation and followup required greater specificity. Therefore, a Project Management team, consisting of the Assistant Director of Social Services (a clinical social worker) and psychiatric nurse clinician (supervisory level) were appointed to this role. While this has provided better coordination and implementation, as the special care unit model has been extended to B and C floors, additional time demands have been difficult for these individuals. HHAR is evaluating a series of possible responses including the development of a "SCU Coordinator" position, increased psychiatric and/or psychology consultation, and additional opportunities for staff education.

Unit Staffing

Staffing on this unit (Table 9) was increased minimally during the planning phase and once again during the first 6 months of the unit's function in response to SCU staff's expressed needs. It should be noted that nurse staffing increases represented an adjustment, rather than an increase in overall staffing allocations within the (total) HHAR approved nurse staffing positions (in excess of 395).

Table 9
Staffing Patterns, GP-1, Prior to SCU
Development and Present

Department	Pre-SCU	Interim Changes with SCU Development	Present Nursing
Days			
Nurses	3	3	3
Aides	4	5	6
Evening			
Nurses	2	2	2
Aides	3	4	4
Nights			
Nurses	1	1	1
Aides	3	3	3
Physician	.6	.6	.6
Social Work	.3	.3	.3
Leisure Time Activities	.5	.5 (office moved onto the SCU)	.5

Staff assignments remained essentially intact. While HHAR offers no salary differential for SCU assignment, attempts have been made for the staff to feel "special". However, despite initial GP-1 staff preparation for conversion to this SCU and their indication of positive feelings about being part of "something special", the actual effect of a 25% increase in the number of demented patients, following the patient transfer process, did create stress and frustration, leading to a temporary decline in staff morale and confidence.

Training

Inasmuch as HHAR has given significant attention to training relevent to the special care needs of patients with dementia since 1981, no special pre-SCU education program was developed. Interdisciplinary staff training programs on all shifts, have previously addressed diagnosis, etiology, clinical course of the disease, management and communication techniques, family response and concerns, and psychopharmacological approaches. Resources for this continuing education have drawn upon Hunter College-Brookdale Center on Aging (specific training grants); Albert Einstein College of Medicine Teaching Nursing Home staff (HHAR is one of the three nursing home sites); College of Mt. St. Vincents nursing program (this college borders HHAR, and has a long-standing relationship for student placements and faculty teaching) and Home staff. These educational efforts are complemented by daily (rotating by unit), (Medical) Teaching - Management Rounds; and on-unit team meetings. Ongoing training now responds to specific articulated needs, e.g. the recent two part program "Differentiating Communication Problems Caused by Aphasia versus Dementia" for nursing, social services and therapy staff.

Other current, identified training needs include additional basic information for the nurse's aide regarding SDAT, group management techniques, and; approaches to caring for the physically aggressive male patient. (The latter is indicative of a recent problem noted within the three special care units.) Currently, the HHAR SCU - Task Force is addressing the possibility of staff replacement through staff volunteering rather than assignment and a pre-service orientation and training module for new staff on the three SCU's.

Activities

Establishment of the activities program required significant cooperation and negotiation between the involved disciplines including Leisure Time Activities, Occupational Therapy, Physical Therapy, and Speech/Audiology. The regularity with which OT/PT participate in daily exercise programs reflects the demands of the rehabilitation therapy programs; posing difficulties for unit scheduling.

To the degree possible, on GP-1, daily on the unit programing is consistent. Activity times are fixed to enhance the time orientation for the patient (Pannala, 1984), staff and families.

A typical day might include:

GP-1

7:00 am - 10:30 am	Breakfast, activities of daily living Medical and Clinic appointments.
10:30 am - 11:15 am	Sensory integration group - Occupational Therapy (OT)
11:15 am - 12:00 noon	Adaptive sports activities - Leisure Time Activities (LTA).

12:00 noon - 1:30 pm	Lunch, toileting, rest time.
1:30 pm - 2:15 pm	Exercise programming including dance therapy, music and movement - LTA, OT/PT (as available)
2:15 pm - 3:00 pm	Cognitive activities (e.g. Verbal games, crafts and reminiscence). - LTA
3:00 pm - 3:45 pm	Communication and/or social activities groups - (e.g., Discourse and Dialogue.) Rotation by LTA, Audiology/Speech Pathology
3:45 pm - 4:30 pm (Tuesday/Thursday)	Music and Wine
5:30 pm -	Dinner
6:00 pm - 7:00 pm (Monday/Wednesday)	After Dinner Music

To the extent possible, programs are brought to the unit, rather than patients brought to the activity. We have found that this reduces anxiety about leaving the familiarity of the unit and maximizes staff resources. The addition of late afternoon music and wine programming has, according to anecdotal report, improved the unit ambiance during the dinner hour. More significant evaluation studies of its impact are in process.

Several unusual programs within the SCU context include Friday afternoon Jewish poetry reading, use of "Walkman-like" radios to reduce verbal disruptive behaviors and "Discourse and Dialogue", conducted weekly by the Director, Audiology/Speech Pathology. Within this 45-60 minute program, "Discourse and Dialogue" combines the underlying principles of communication-cognition programs, and the techniques usually associated with aphasia therapy, reality orientation and group therapy dynamics. Specifically, 6-8 women categorized into stages 5-6 (Global Deterioration Scale, Reisberg, 1985), meet and discuss items of interest ranging from gardening, Israel and child-raising - to maintain their language pragmatics and the ability to adult dialogue.

As had been indicated earlier, the serious knowledge void of both defining the success of an activity (in concrete terms) and predicting differential success by activity, functional patient level and staff leader, marks a very critical next step for HHAR (and hopefully others in the field).

As the program and care model on GP-1 continues to be refined, efforts have also been made to extend this approach to the "original" special infirmary units, i.e. B and C floors. Regular team meeting were instituted on these units, in late 1985 to provide the ground work for the conversion to the more comprehensive therapeutic model. It should be noted that these units suffer from an "environmental stigma"; it is the Infirmary Building whose repacement is imminent due to physical plant obsolescence. Additionally, B and C floors are also staffed by aides of long tenure, creating an expected "tug" between resistance to change and excitement. In addition to complete extension of the model program activities to B and C floors, future goals include continued programmatic and management innovation including: the training of nurse's aides to conduct sensory integration groups; weekend programs; smaller and more innovative group programs; the implementation and evaluation of a generic health care worker (or nurse aide centered) approach to care, introduction of finger foods to improve nourishment; evaluation of homogeneous versus heterogeneous placement of patients with dementia, increased utilization of family members as volunteers and; evaluation of specific therapeutic approaches on patients, family and staff.

SCU Overview

The actual preparation of this report provided an opportunity and motivation for retrospective patient data analysis.

Demographically, as indicated in Tables 10 and 11, the three special care units have a slightly higher proportion of male patients than the overall HHAR SNF ratios, i.e. 21% male versus 18% male respectively. Similarly, while the average age of HHAR's - SNF population is 88 years, the average age of its SCU population is 84.6 years. Staff reports and concerns regarding the increased numbers of younger males with aggressive behaviors, are consistent with these data reports and require considerable thought regarding therapeutic

Table 10

Gender Comparison Between SCU Patients and All SNF Patients, 1985

	Male		Female	
	Number	%	Number	%
SNF-Special Care Unit				
GP-1	10	24%	32	75%
B	10	20%	39	80%
C	9	18%	40	72%
SNF-Excluding SCU Patients	59	17%	285	83%
All SNF	88	18%	396	82%

Table 11

Age Comparison of SCU Patients and Other HHAR SNF Patients

Special Care Unit	Average Age (years)
GP-1	83.7
B	84.3
C	85.7
Two traditional SNF units, selected for comparison*	
GP-2	87.3
P6	87.0
All SNF patients regardless of dianosis	88.0

Note: GP-2, P-6 patients include those with psychiatric diagnoses only interventions and supportive environmental strategies. It is anticipated that this problem will increase, in light of community needs and limited resources.

Consistent with initial planning, priority has been given for SCU admissions to HHAR intra-institutional transfers; 49% of the current SCU population was so admitted. (see Table 12) Within HHAR's traditional SNF units, only 35% of the admissions were intra-institutional transfers in November, 1985. Currently, there are 18 HHAR SNF patients awaiting SCU placement. Differences in sources of admission between the three SCU's are a function of environmental differences and, as noted earlier, in the unit's relative ability to prevent wandering. (B floor is the most open; C floor exits are alarmed but offer little wandering space; GP-1 is protected and offers wandering paths).

While admissions criteria to the three HHAR-SCUs, were to have been consistent, assessment of the Case Mix Index* for December 1985 and a recent functional assessment do suggest a greater impairment level on B and C floors. (Table 13)

This, in combination with sources of admission, indicates that GP-1 has been utilized primarily for in-house transfers (wherein patient/family expectations are high regarding the environment), while B and C floors accept more direct admissions for whom there are no such expectations (the reader is reminded of the new building construction to replace B and C floors).

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*Note: Case mix indices (CMI) are calculated in New York State in accordance with recently developed RUGs II assessment and reimbursement criteria. Theoretically a CMI of 1 is the state-wide SNF norm.

TABLE 12

Comparison of Admission Source of SCU Patients with All HHAR-SNF Admissions

Admission Source	SCU- CURRENT PATIENT POPULATION								TOTAL SNF- 1984, and SAMPL MONTH			
	GP - 1 N = 42		B N = 49		C N = 49		Total N = 140		1984 N=151		Nov,19 N=26	
	#	%	#	%	#	%	#	%	#	%	#	%
Intra Instit. Transfer	31	74	9	18	28	57	68	49	74	(49)	9	(31
Community (own home)	7	17	20	41	10	20	37	26	39	(25)	9	(31
Hospital	3	7	13	27	9	18	25	18	28	(18)	6	(23
(Other) Nursing Home	1	2	6	12	2	4	9	6	10	(6)	2	(7)
Adult Home - HRF	0	0	1	2	0	0	1	1	0		0	

Table 13
Comparison of Functional Ability and CMI Between HHAR's Three SCUs

	Case Mix Index	Patients Requiring Total Assistance*			
		Transfer	Eating/Feeding	Tolieting	Dressing
GP-1**	1.09	6 (14%)	25 (60%)	5 (12%)	13 (31%)
B	1.19	48 (98%)	25 (51%)	48 (98%)	48 (98%)
C	1.30	45 (94%)	33 (69%)	48 (100%)	43 (100%)

Notes: *All others require partial assistance.
**Based upon census of 42, 49, 48 respectively.

Length of stay (LOS) information is also important for facility planning, as (Table 14) as it suggests "turnover" rates for SCUs/SNFs. Further, such data provides indications for specific facility SCU bed need.

Diagnosis and Management

An overview of the psychiatric disorders (organic and functional) of SCU patients are presented in Table 16, with two "traditional" SNF units presented for comparison. As was anticipated based upon the epidemiological literature (Larson et. al., 1984, Larson, et. al., 1985) 89% of the patients with dementia are diagnosed as "probable SDAT," and 10% with "mixed dementia." Also expected was the 50% proportion of non-SCU patients with psychiatric diagnoses.

Management approaches on the SCU include, as indicated previously, environmental supports, creation of a therapeutic milieu, activity programs, etc. Psychotropic drugs are also viewed as an effective and important component of patient management when appropriately titrated and not utilized to replace human interventions (Marletta, 1985). Table 17 details psychotropic drug orders in effect on 1/12/86 on the three SCU's and compares these to the two other "typical" SNF units. While studies are not available to establish norms or standards for prescribing patterns within institutional SCU's, we believe the proportion of patients not on psychotropic drugs (60%) is appropriate to the delicate balance between under/appropriate/over medication. Overall drug utilization is also low on the SCU's; the average number of drugs is 4.3 versus 5.6 for all HHAR SNF units.*

Note: This includes all prescription, controlled substances, over the counter and prn medications, calculated for quarter 3, 1985.

Table 14

Length of Stay Comparisons - 1985*

Length of Stay Category	# of Individuals	Years
Total Institutional LOS (HRF + SNF)	188	4.5
For all residents residing within the HRF	19	2.6
For all patients expiring within the SCU	56	5.4
LOS on the SCU only, for patients expiring in 1985	56	2.9
For all patients expiring within the "traditional" SNF	113	4.3

Note: LOS calculations are based upon the 188 HHAR patients expiring in 1985.

Table 15

Transfer Patterns of Patients Expiring Within HHAR - SCUs, 1985

Unit	Total # Patients Expiring	Transfer Pattern		
		HRF--SNF--SCU	SNF--SCU	Admitted Directly to SCU
B	23	7 (30%)	7 (30%)	9 (40%)
C	19	3 (16%)	8 (42%)	8 (42%)
GP-1	14	9 (64%)	5 (36%)	0
Total	56	19 (34%)	20 (36%)	17 (30%)

Note: No patient placed on the GP-1, SCU directly from the community from May 1984 to December 1985 has yet expired.

TABLE 16

Comparison of Psychiatric Diagnostic Categories of SCU Patients With "Traditional" SNF Patients

	Special Care Units						Total		Traditional SNF			
	GP1(N=42)		B (N=49)		C(N=49)		SCU(N=140)		GP 2(N=40)		P 6(N=53)	
	#		#	%	#	%	#	%	#	%	#	%
Prob.SDAT	41	(98%)	40	(82%)	44	(90%)	125	(89%)	13	(33%)	13	(25%)
Prob. SDAT With MID	0	0	9	(18%)	5	(10%)	14	(10%)	1	(2%)	0	0
Depression	0	0	0	0	0	0	0	0	9	(23%)	7	(13%)
Schizoph.	1	(2%)	0	0	0	0	1	(1%)	0	0	0	0
Anxiety	0	0	0	0	0	0	0	0	0	0	1	(2%)
Total	42		49		49		140		23	(57%)	27	(51%)

Note: The diagnosis utilized is the primary psychiatric diagnosis noted by the physician.

TABLE 17

Comparison of Psychotropic Drug Orders for Patients with Psychiatric Diagnoses on SCUs & "Traditional" SNF Units

	Special Care Units								Traditional SNF Units			
	GP 1(N=42)		B(N=49)		C(N=49)		Total (N=140)		GP 2(N=40)		P 6(N=53)	
	#	%	#	%	#	%	#	%	#	%	#	%
Anti Psychotics												
Standing	8	(19%)	11	(22%)	10	(20%)	29	(21%)	1	(3%)	4	(8%)
PRN	1	(2%)	0	0	0	0	1	0	0	0	0	0
Anti Depressants	1	(2%)	5	(10%)	4	(8%)	10	(7%)	5	(12%)	4	(8%)
Tranqualizers												
Standing	6	(15%)	2	(5%)	4	(8%)	12	(9%)	1	(3%)	2	(3%)
PRN	0	0	0	0	0	0	0	0	0	0	0	0
Sleep												
Standing	1	(2%)	3	(6%)	2	(4%)	6	(4%)	0	0	10	(19%)
PRN	0	0	0	0	1	(2%)	1	0	0	0	0	0
Total # Psych. Drugs	17	(40%)	21	(43%)	21	(42%)	59	(42%)	7	(18%)	20	(38%)
Total # Pts. on Psych.Drugs	17	(40%)	18	(37%)	19	(39%)	54	(39%)	7	(18%)	16	(30%)
Total # Pts. Not on Psych. Drugs with psychiatric diagnoses	25	(60%)	31	(63%)	30	(61%)	86	(61%)	16	(40%)	11	(21%)

It should be noted that two physicians are responsible for SCU care and utilize psychiatric consultation for evaluation, medication, titration and review. Psychiatric consultation use on the SCU's is stable and divided between bi-monthly medication reviews, recalls and (minimally) consultation requests. The rate of psychiatric consultation is consistent between HHAR's traditional SNF units and the SCU's - i.e. 10% /month. This requires approximately four hours per month per SCU by the HHAR psychiatrist.

Restraint use also requires that balance between individual protection and undue personal restriction. Table 18 documents HHAR's restraint order patterns. While the proportion of individuals with standing restraint orders exceeds 56%, we suggest it to be a function of end-stage dysfunctions as a result of the disease. Again while there are no standards for restraint use this data analysis has prompted HHAR SCU staff to more critically review such orders.

As has been emphasized throughout this document, there are not yet standards or outcome measures relative to the impact of therapeutic interventions for patients with dementia. From the inception of GP-1 as a SCU, data reports of patient screams, number of patients requesting assistance and accidents and incidents were maintained with the potential to establish HHAR - base line reports. The first two measures reflect disorientation and agitating behaviors, amenable we believe, to intervention and clearly detrimental to the creation of a therapeutic environment.

Screaming behavior has declined substantially on GP-1 since the creation of the SCU. (Table 19, Chart 1) To measure this, an observer, usually the HHAR

TABLE 18

Comparison of Restraint Orders for Patients with Psychiatric Diagnosis on SCUs & "Traditional" SNF Units

	Special Care Units				Traditional SNF Units		
	GP 1 N=42 # %	B N=49 # %	C N=49 # %	Total N=140 # %	GP 2* N=23 # %	P 6* N=27 # %	Total* N=50 # %
Standing Orders	13-(31%)	30-(61%)	35-(71%)	78-(56%)	6-(26%)	2-(7%)	8-(16%)
PRN Orders	16-(38%)	12-(24%)	12-(24%)	30-(21%)	0 0	2-(7%)	2-(4%)
Total # Restr. Orders	29-(69%)	42-(86%)	49-(1.%)	120-(86%)	6-(26%)	4-(15%)	10-(20%)
Total # Pts. Restr.	29-(69%)	42-(86%)	47-(96%)	118-(84%)	6-(26%)	4-(15%)	10-(20%)
# Pts. with Psychiatric Diag. without Standing Restr. orders.	13-(31%)	7-(14%)	2-(4%)	22-(16%)	17-(74%)	23-(85%)	40-(80%)

*Patients with Psychiatric Diagnosis

Table 19

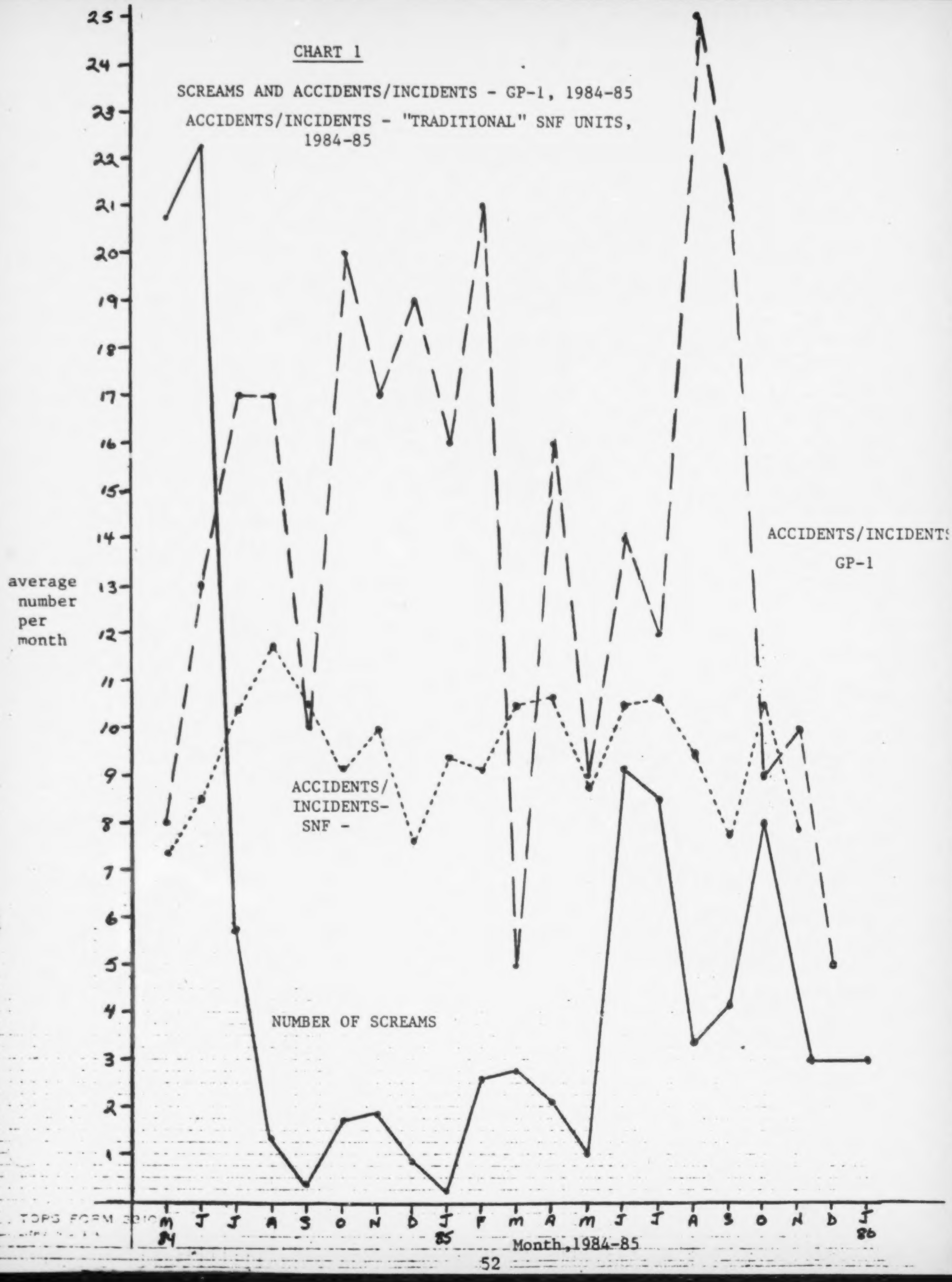
Screams and Patients Asking for Help as Indices of Behavior "Management Problems", GP-1, 1984-85

Month	# Days Of Observation	Screams		People Screaming		Patients Asking For Help	
		#	$\bar{X}$	#	$\bar{X}$	#	$\bar{X}$
May '84	6	125	20.8	6	3.	6	3
June '84	11	244	22.2	43	3.9	30	2.7
July '84	17	97	5.7	27	1.6	23	1.3
Aug. '84	13	17	1.3	10	.6	13	.8
Sept.'84	13	6	.3	5	.4	6	.5
Oct. '84	14	25	1.7	11	.8	6	.4
Nov. '84	14	27	1.9	16	1.1	21	1.5
Dec. '84	13	10	.8	11	.8	4	.3
Jan. '85	15	3	.2	1	.1	1	.1
Feb. '85	18	13	2.6	7	1.	3	.4
Mar. '85	15	38	2.5	21	1.4	11	.7
Apr. '85	11	24	2.1	8	.7	0	0
May '85	11	12	1.0	5	.5	0	0
June '85	10	92	9.2	14	1.4	3	.3
July '85	11	93	8.5	21	1.9	7	.6
Aug. '85	6	20	3.3	5	.8	7	1.2
Sept.'85	9	37	4.1	8	.9	17	1.8
Oct. '85	8	72	8.	18	2.	3	.3
Jan. '86	2	6	3.				

Note: Measures were taken at least 7 (random) days/month, by an observer located on the unit, for 5 minutes, at 3 p.m. (shift change). This individual walked the periphery of the unit, at least once, and stayed in the lounge area the remainder of the time.

CHART 1

SCREAMS AND ACCIDENTS/INCIDENTS - GP-1, 1984-85
ACCIDENTS/INCIDENTS - "TRADITIONAL" SNF UNITS, 1984-85



Research Director or a research student, was placed on the SCU for 5 minutes, at shift change (i.e. 3 p.m.). Their routine included walking the unit's perimeter, standing in the day room, and counting.

Variations from the lower plateau coincide with peak vacation periods (notable also for number of accidents) suggestive of the impact of vacation staff coverage for this disoriented population.

Accident and incident rates have not shown similar dramatic declines. We interpret this data to be a function of our reluctance to overmedicate and overrestrain this population, its increased frailty, (Brody, et, al, 1984) and the Home's policy to report as accidents and incidents, any occurrence regardless if injury has been sustained.

IV. CONCLUSION

The special care unit approach to care for the institutionalized patient with dementia is becoming recognized as a viable, perhaps even cost effective approach to caring for this population. While specific program and organizational components must reflect an institution's own style, the essential core of SCU development includes: delineation of objectives; admission and discharge criteria; use of an assessment instrument; environmental supports; special programs; staff training, and; family supports. However, even with this core, and anecdotal reports of clinical success, the differential benefits of programming and staffing approaches have not been evaluated. Further, standards or outcomes of positive care have not been established for this population. These represent obvious, sequential steps to follow given the now existing, articulated organizational options for the care of individuals with dementia.

As long as programs or units for the care of this population are viewed as "special" there is a serious facility responsibility for diligent planning, continuous monitoring, re-evaluation, innovation, compassion and sensitivity.

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Appendices

A - Facilities Participating in National Survey

B - Survey Tools

C - Monograph-1983 HHAR Symposium on Alzheimer's Disease and Related Disorders

D - HHAR Criteria for Admission to the SCU

APPENDIX A

Facilities Self-Identifying Through Hebrew Home for the Aged at Riverdale-Brookdale Study as Having Special Units or Special Programs for Individuals With Alzheimer's Disease

Non-Profit Facilities, Designated Special Units for Individuals With Dementia

Daughters of Israel Geriatric Center 1155 Pleasant Valley Way West Orange, New Jersey 07052	201-721-5100
Greenwood House - Home for the Jewish Aged 53 Walter Street Trenton, New Jersey 08628	609-883-5391
The Hebrew Home for the Aged at Riverdale 5901 Palisade Avenue Bronx, New York 10471	212-549-8700
Morningside House 1000 Pelham Parkway Bronx, New York 10461	212-863-5800
New York Medical College Ruth Taylor Institute 25 Bradhurst Avenue Hawthorne, New York 10532	914-347-7728
Rosa Coplon Jewish Home & Infirmary 10 Symphony Circle Buffalo, New York 14201	716-885-3311
Jewish Home for the Elderly 175 Jefferson Street Fairfield, Conn. 06432	203-373-9461
Wesley Holmes Budd Terrace 1833 Clifton Road, N.E. Atlanta, GA 30029	404-325-2988
Philadelphia Geriatric Center 5301 Old York Road Philadelphia, PA 19141	215-456-2900
Hebrew Home of Greater Washington 6121 Montrose Road Rockville, Maryland 20852	301-881-0300
Meridian - Heritage Nursing Center German Hill Road Dunkirk, Maryland 21229	301-282-6310

Green Hills Center
6557 U.S. 68 South
West Liberty, Ohio 43357 513-465-5065

Menorah Park Center for the Aging
27100 Cedar Road
Beachwood, Ohio 44122 216-831-6500

The Indianapolis Jewish Home, Inc.
(Hooverwood)
7001 Hoover Road
Indianapolis, Indiana 46260 317-251-2261

Seven Acres - Jewish Home for the Aged
6200 North Braeswood
Houston, Texas 77674 713-771-4111

Jewish Geriatric & Convalescent Center
7801 Holmes Road
Kansas City, MO 64131 816-333-7800

Ebenezer Caroline Center
110 East 18th Street
Minneapolis, Minn 55403 612-879-2800

Rainbow Center, Glenwood Retirement Home
719 S.E. Second Street
Glenwood, Minnesota 55334 612-634-5131

Marian Catholic Home
3333 West Hyland Boulevard
Milwaukee, WI 53208 414-344-8100

Milwaukee Jewish Home
1414 N. Prospect Avenue
Milwaukee, WI 53202 414-276-2627

Handmaker Jewish Geriatric Center
2221 North Rosemont Boulevard
Tucson, AZ 85712 602-881-2323

St. John of God Nursing Hospital & Residence
2035 W. Adams Boulevard
Los Angeles, California 90018 213-731-0641

Motion Picture & Television Hospital
23450 Calabasas Road
Woodland Hill, CA 91364 818-347-1591

Non-Profit Facilities Indicating Special Programs for Individuals With Dementia

Beth Abraham Hospital
612 Allerton Avenue
Bronx, New York 10467 212-920-5881

Margaret Tietz Center for Nursing Care
164-11 Chapin Parkway
Jamaica, New York 11432 718-523-6400

Hebrew Rehabilitation Center for the Aged
1200 Centre Street
Boston (Roslindale), MA 02131 617-325-8000

Levindale Hebrew Geriatric Center & 301-466-8700
Hospital
Belvedere and Greenspring Streets
Baltimore, MD 21215

Taylor Care Center 904-731-8230
6535 Chester Avenue
Jacksonville, Fla. 32217

Benedictine Nursing Center 503-845-6841
540 South Main Street
Mount Angel, OR 97362

Jewish Homes for the Aging of 818-881-4411
Greater Los Angeles
18855 Victory Blvd.
Reseda, CA 91335

Walnut Manor
891 South Walnut Avenue
Anaheim, CA 92802 714-776-7150

Proprietary Facilities With Special Care Units For Dementia Patients

Courtland Gardens Retirement Residence 203-359-2000
59 Courtland Avenue
Stanford, CT 06902

Fairfield Manor Health Care Center 203-853-0010
23 Prospect Avenue
Norwalk, CT 06850
(in planning stages)

Fishkill Health Related Center, Inc. 914-831-8704
Route 9D and Dogwood Lane
Beacon, New York 12508

Hillhaven Corporation has 12 to 15 active special units scattered about the country. Their "models" include, Newton-Wesley, Kansas City, Phoenix, Denver, Portland, and San Francisco.

The Hebrew Home for the Aged at Riverdale notes with gratitude the cooperation and assistance of these facilities in completing this survey.

Appendix B

Facility Name:____________________________

Address:____________________________

Telephone Number:____________________________

Contact Person:____________________________

1. A. In total, how many beds are in your facility?
   _____SNF
   _____ICF/HRF

   B. In total, how many units are in your faciltiy?
   _____SNF
   _____ICF/HRF

   C. Is your facility - non-profit,__________ proprietary? __________

2. How many units do you have for patients with dementia? _____

3. How is your special care unit(s) for individuals with dementia organized?

   A. Number of beds/unit _____

   B. Level of Care

   _____SNF
   _____ICF/HRF

4. When were your unit(s) opened? __________

5. What are your criteria for admission/discharge to and from the Special Care Unit? (Please specify functional/behavioral, age, source of payment, and if priority is given to in-house transfers.)

   A. Admission

   B. Discharge

6. If you have more than one Special Care Unit, are the criteria for admission/discharge the same for each unit? (If different, please specify.)

7. Did you convert a traditional SNF/ICF unit to create this Special Care Unit?

YES _____ NO _____

If yes, what environmental changes did you make?

8. Please describe any unusual aspects of the environment (not noted in #7 above) related to security, noise control, orientation, sensory stimulation, etc.

9. Please describe a typical day's activity schedule.

10. What is the unit's staffing pattern? (Please include all patient care disciplines.)

Day: ______________________________
____
____

Evening: ______________________________
____
____

Night: ______________________________
____
____

11. Do you provide any supports or education for families? (If yes, please specify.)

12. Do you provide any special training or supports for unit staff? If yes, please specify.

13. Do you have a special name for the unit?

14. A. What is your daily charge/rate for this unit? ___________

    B. Is the rate the same as "traditional ICF/SNF" daily rate?

       ______ YES ______ NO

       If no, please indicate the differential.

    C. Are your costs equivalent to your rate?

       ______ YES ______ NO

       If no, please indicate actual (or approximate actual) costs.

15. Are you presently conducting any research about this unit? If yes, please describe briefly.

16. Do you provide any community-based services for this population? (If yes, please specify)

17. Please specify your age criteria for admission to the facility at large, as well as special care unit for dementia.

18. Do you have an individual in your facility who has administrative or clinical responsibility for the special care units? If you, please indicate their title, other responsibilities, training. If this individual was employed after the development of special care units, time allocation for special care unit programs, etc.

19. Other comments.

Thank you for your cooperation and assistance. A stamped, self-addressed envelope is included for your convenience.

Questionnaire A
Facilities with Discrete or Special Units for Patients with Dementia

Facility Name:__________________________________

Address:_______________________________________

Telephone Number:_____________________________

Contact Person:________________________________

1. A. In total, how many beds are in your facility?
   _____SNF
   _____ICF/HRF

   B. In total, how many units are in your facility?
   _____SNF
   _____ICF/HRF

   C. Is your facility - non-profit,-_________ proprietary? ________

2. How many units do you have for patients with dementia? _____

3. How is your special care unit(s) for individuals with dementia organized?

   A. Number of beds/unit _____

   B. Level of Care

   _____SNF

   _____ICF/HRF

4. When were your unit(s) opened? ________________

5. What are your criteria for admission/discharge to and from the Special Care Unit? (Please specify functional/behavioral, age, source of payment, and if priority is given to in-house transfers.)

   A. Admission

   B. Discharge

6. If you have more than one Special Care Unit, are the criteria for admissio discharge the same for each unit? (If different, please specify.)

7. Did you convert a traditional SNF/ICF unit to create this Special Care Unit?

YES_____ NO_____

If yes, what environmental changes did you make?

8. Please describe any unusual aspects of the environment (not noted in #7 above) related to security, noise control, orientation, sensory stimulation, etc.

9. Please describe a typical day's activity schedule.

10. What is the unit's staffing pattern? (Please include all patient care disciplines.)

Day:______________________________
____
____

Evening:______________________________
____
____

Night:______________________________
____
____

11. Do you provide any supports or education for families? (If yes, please specify.)

12. Do you provide any special training or supports for staff working with patients with dementia? If yes, please specify.

13. Do you have a special name for the unit?

14. A. What is your daily charge/rate for this unit? ____________

B. Is the rate the same as "traditional ICF/SNF" daily rate? __YES __NO

If no, please indicate the differential.

C. Are your costs equivalent to your rate? __YES __NO

If no, please indicate actual (or approximate actual) costs.

15. Are you presently conducting any research about patients with dementia?

If yes, please describe briefly.

16. Do you provide any community-based services for this population? (If yes, please specify)

17. Other comments.

18. Do you have any questions about the Hebrew Home for the Aged at Riverdale's Special Care Unit?

Thank you for your cooperation and assistance. A stamped, self-addressed envelope is included for your convenience.

Questionnaire B
Facilities with Special Programs
(Not Special Units) for Patients with Dementia

Facility Name: ________________________________

Address: ________________________________

Telephone Number: ________________________________

Contact Person: ________________________________

1. A. In total, how many beds are in your facility?
    _____SNF
    _____ICF/HRF

   B. In total, how many units are in your facility?
    _____SNF
    _____ICF/HRF

   C. Is your facility - non-profit, _______ proprietary? ________

2. How many individuals in your facility have a diagnosis of dementia?
   _____SNF
   _____ICF/HRF

3. Please describe your special programs including goal, schedules, staffing, costs, etc.

4. Do you provide any supports or education for families? (If yes, please specify.)

5. Do you provide any special training or supports for staff working with patients with dementia? If yes, please specify.

6. Are you presently conducting any research about patients with dementia?

   If yes, please describe briefly.

7. Do you provide any community-based services for this population?
(If yes, please specify)

8. Have you considered establishing a special unit for patients with dementia

_____YES _____NO

If yes, why did you not choose this option?

9. Other comments.

10. Do you have any questions about the Hebrew Home for the Aged at Riverdale's Special Care Unit?

Thank you for your cooperation and assistance. A stamped, self-addressed envelope is included for your convenience.

Appendix C

The Martin Steinberg Inaugural Memorial Symposium on Alzheimer's Disease and Related Disorders

A Monograph

The Hebrew Home for the Aged in Riverdale
November 5, 1983

This monograph is
dedicated to the
memory of
Mr. Martin Steinberg

5/119

The Hebrew Home for the Aged in Riverdale

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The papers that follow were presented at
The Martin Steinberg Inaugural Memorial Symposium on Alzheimer's Disease and Related Disorders
held on September 21, 1983 at the Hebrew Home for the Aged in Riverdale.

Welcoming Remarks

Jacob Reingold, M.S.
Executive Vice President
The Hebrew Home for the Aged in Riverdale
Panelist

Welcome distinguished guests, colleagues, members of the press, to the first Martin Steinberg Memorial Symposium on Alzheimer's Disease and Related Disorders. I am proud that the Hebrew Home for the Aged in Riverdale is the first institution for long-term care to direct its efforts towards informing the professional community and the general public about the threat of this little known disease that ravages more than ½ million Americans yearly.

Only a short time ago, as you know, a discussion of senility would never make newspaper headlines or claim valuable, saleable TV time. Everyone thought that becoming senile was something all elderly persons had the misfortune to look forward to as they advanced in age. It was not until the discovery and subsequent years of research into senile dementia that Alzheimer's Disease was isolated as a *disease*, which can strike at any age, but strikes the elderly most frequently of all. Alzheimer's Disease is attracting media attention. Research and treatment has become a national priority because the disease is perceived by our leaders and our medical profession as a potential threat to each of us as we age and a very real threat to our economy because of an anticipated increased need for institutional care for Alzheimer's victims.

We have come a long way since the forgetfulness, confusion and irritability of an elderly person would be swept aside with a single remark—he's just getting senile. Everyone ages, but no one has to get senile. That's what today's conference is all about. You will hear respected professionals tell you what they know and what remains a mystery about Alzheimer's Disease. They will discuss different treatments and methodologies, and they will explore social, ethical, political and economic problems of treating the Alzheimer's victim as well as dealing with the confused and care-ridden families. You will also learn what we at The Hebrew Home for the Aged in Riverdale are doing to unravel the mystery of Alzheimer's Disease, and to eliminate senility from the medical lexicon.

Thank you for coming.

Alzheimer's Disease—Ancient Problem, Recent Discoveries

by Carl Eisdorfer, Ph.D., M.D.
President, Montefiore Medical Center
Professor, Department of Psychiatry and Neuroscience
Albert Einstein College of Medicine

The title of this seminar on Alzheimer's Disease, "Ancient Problem, Recent Discoveries," is, I think, beautifully articulated. My role is to introduce this concept, to give you a flavor of what it is we're dealing with, but not to say too much and cut into the important talks that are to follow. I'll start with a comment that I've made several times because I think it needs to be understood. We have for centuries accepted the inevitability of profound intellectual and cognitive decline.

Basically, we talk about a demented state. In *Mankind and Mother Earth*, that important volume by Arnold Toynbee, he tells us that man has a choice between death and senility. The first point to be made—perhaps the most important point—is that this is nonsense. We have not understood that dementia is not a normal process, that the choice is simply not between death and dementia, any more than cancer or heart disease or high levels of infant mortality are inevitable. We need to change our mind-set.

The term senility implies two things, neither of which is true. It implies the inevitability of dementia, and it implies that if a person is demented there is nothing we can do for that individual. In most instances there are *many* things we can do.

There are a whole variety of dementing disorders. We're discussing just the non-reversible ones. The major non-reversible form of dementia is the Alzheimer's type, and I use the term *type* advisedly. We're still not sure of what happens in later life when the brain appears for the moment to be identical with an Alzheimer's brain. The disease process may be a quite accelerated rate of aging. It's still a disease; these are merely descriptive terms. In aging, what we really have is the loss of neuronal tissue for reasons unknown.

If we accept that senility is inevitable, then nothing needs to be done. Why bother examining the patient? Health care costs are too high in the United States. Costs for hospital beds are too high; psychiatrists, neurologists, even neuropathologists are too expensive; so why bother? Why not just put these patients away and not worry about them? Well, for a variety of reasons, most of which I've already alluded to. Every patient with a cognitive disorder deserves a comprehensive medical evaluation, with the appropriate laboratory measures, appropriate neurological evaluation, and I would add a psycho-social component.

Can we do anything about dementia? Well, if in fact the dementia is caused by a reversible condition, whether it's a side effect of medication, too many medications, the wrong medication, or a disease, surely you can reverse dementia. Let me tell you what my concern is. With the help of the ADRDA, the Alzheimer's Disease and Related Disorders Association, I think we have seen a very significant shift from the use of the term senility to the use of the term Alzheimer's Disease. All to the good. Except I'm beginning to hear people use *Alzheimer's Disease* in the same way they used *senility*. And that would be a tragedy. It is not just a substitution of words we're talking about; it's the substitution of a concept. And unless we substitute the concept, the word is meaningless. So the first thing is, the cause of dementia may be reversible; not all dementia is Alzheimer's Disease. Secondly, one of the things that we see is the concurrence of disorders. Most of the patients with Alzheimer's Disease, even the early onset, tend to be older in life, and often have concurrent diseases. These diseases include the flu, pneumonia, or having a fever that's not readily detectable because older people have an unreliable thermoregulation system. All of these in the face of a true or non-reversible dementia will make the dementia much worse. So a patient with Alzheimer's Disease who's depressed is a much more cognitively impaired patient than someone with Alzheimer's Disease who's not depressed. Do you treat the depression or not? Do you ignore the depression just because the patient has Alzheimer's Disease; do you ignore the pneumonia because the patient has Alzheimer's Disease? Do you throw away your prescription pad and take a random guess at how much medication the patient should have because the patient has Alzheimer's Disease? Quite the opposite is true.

Because we know that the patient has brain impairment, we have to be more sensitive about the psychological, social, familial, medical and medicinal aspects of their care. And then finally we have an important responsibility. The obligation is not only to find out more about the disease, but to find out more about the clinical management of the patient. And that obligation is one that the country has only recently undertaken.

Can we do anything with these patients? By now we have data from Einstein, we have data from NYU, we have data from Seattle, we have data from San Francisco. We're beginning to recognize that if we *try* to make a difference we *can* make a difference. And that therapy works. Family therapy works because the family becomes the center of support. Institution-based therapy works. And medications may work, though they've got to be administered carefully. If you say somebody has Alzheimer's Disease does that mean you withhold treatment? No. It means your obligation to provide quality care increases.

What do we know about the disease? The one thing we do know is that the probability of getting the disease, if you live long enough, gets to be higher and higher as you get older. Inevitable? No. Increasing? Yes. We know that probably about half the patients in long-term care in the United States have a significantly dementing illness, and probably the majority of that group has Alzheimer's Disease. We also know that for the first time since the 1950s, we now have more long-term care patients in the United States, there are more long-term care beds, than there are general hospitals. There are about 1.3 million Americans in long-term care. About 1.2 of them are over the age of 65, and, as I've said, the majority of that group have a dementing illness, complicating whatever else they have. There are hopes. Only a few years ago the Alzheimer's Disease and Related Disorders Society was founded nationally, and has become a rapidly growing program. The National Institute on Aging and the National Institute of Neurologic Diseases have begun to invest money in this disorder; the National Institute of Mental Health has shown some concern. And finally the Secretary of Health and Human Services has recognized that this is a disorder meriting national attention. So we are now taking an old problem, and saying it's important enough to warrant our attention.

Current Research

by Robert Terry, M.D.
Professor and Chairman
Department of Pathology
Albert Einstein College of Medicine
Panelist

My predecessors this morning have spoken to you about the frequency of Alzheimer's Disease, its diagnosis, and something about its cost, but no one has yet mentioned its therapy. The question still remains: what can we do about this disease? Well, until recently, we essentially ignored it, and I guess we could continue to do that. We could continue to do what we are doing now; that is, caring for patients; and we can improve that care in many ways. We can continue to observe these patients with ever-increasing detail. But we will still watch their numbers increase, and we will watch the cost—both emotional and economic cost—increase. Or, we can take the third alternative, and that is, to make a significant investment in laboratory research. This was the choice that faced the country not too long ago in regard to infantile paralysis, when great numbers of physicians and lay people were wrapped up (no pun intended) in the Sister Kenny treatments, in which hot packs were applied and physiotherapy was used. But the numbers of polio cases just increased until, ultimately, laboratory workers isolated the virus and made a vaccine against it, so that polio has disappeared as a problem. Now, Alzheimer's Disease is proving to be a somewhat more difficult problem to solve, but I suggest to you that research is our only hope, because watching those numbers and those costs increase will only allow us to be overwhelmed, and in the not too distant future.

Well, what are the general areas where progress has been made in the last couple of decades? About half the patients with dementia who come to autopsy (and autopsy is still the only ultimate proof) have Alzheimer's Disease; another twenty or so percent have multiple infarcts in the brain, and another ten or fifteen percent have a mixture. Those left over have a variety of organic causes of dementia, and a small but significant number have dementia based on some unknown or unfindable cause. To put Alzheimer's Disease in further context, I would remind you that more people die of, or at least with, severe Alzheimer's Disease than die of carcinoma of the lung—the most common fatal cancer in the country today. Alzheimer's is about ten times as common as multiple sclerosis, about a hundred times more common than amyotrophic lateral sclerosis or Huntington's disease. It's a disaster, and it's a major one.

One of the two major microscopic features of Alzheimer's Disease is the neurofibrillary tangle. This is a lesion or abnormality that lies within the cell body of the large and medium-sized neurons of certain parts of the brain. Not all parts of the brain are affected. The tangle is made up of abnormal fibers which are in fact paired helical filaments. It is incumbent upon us in the laboratories to determine the nature of these neurofibrillary tangles, and we've been working at it for twenty years. Some progress is being made. We want to find out what it's made of, because if it is a new kind of protein, it would mean that there is new genetic information. That is the only way a cell can make an entirely new kind of protein. Now the genetic information may actually have been there all the time, but it was repressed, and then it becomes uncovered or de-repressed. We would like to know why and how it becomes uncovered. Or we would like to know how this new genetic information gets inserted into the cell—perhaps by a virus. Now if, on the other hand, this is a normal protein which has been modified in the process of its synthesis, then we would have to look in another direction for the reasons for its becoming modified, becoming insoluble, and becoming detrimental to the normal functions of those nerve cells that are affected. Alzheimer's Disease concerns primarily tissues and cells, and this leads to disordered chemistry, and that leads to the clinical symptoms described by the preceding speakers.

Now one of the ways to get at the nature of these fibers is to homogenize the brain tissue and analyze it chemically, but this has been progressing slowly. That is because these fibers turn out to be very insoluble. They are very resistant to the usual solvents which can dissolve normal fibrous proteins. Another way of getting at it is to use specific antibodies as markers. Many such antibodies have been made which react with the neurofibrillary tangle to help us to identify its protein. So far, although we are making very real progress in identifying this protein, we still cannot answer the question which we posed about fifteen years ago: Is it a normal modified protein, or is it an abnormal protein?

The neuritic or senile plaque is the second marker, described even before Alzheimer, but recognized by Alzheimer as being a major component of the changes which occur in this disease. This plaque has a center made up of amyloid, which is an abnormal fibrous protein in the form of very delicate filaments in between the cells. We are looking for the nature of that amyloid. We would like to know where it comes from, and how it gets there. Surrounding the central amyloid of the plaque are abnormal branches of nerve cells which we can call, in general, neurites. In fact, most of them are the axonal endings, that is, the transmitter ending of the cell. These terminals are ballooned and they contain abnormal mitochondria and structures called lysosomes, which hold a certain group of enzymes, and the neurites also contain paired helical filaments identical to those of the tangle. So there is also a great deal to be done in regard to understanding the plaque.

But we do know that the concentration of the plaques, or for that matter of the tangles, per unit area in the brain parallels very closely the degree of severity of the dementia as measured by the clinicians. That doesn't prove a causal relationship. Even after seventy-five years of this disease having been known, one cannot say that the tangles and the plaques cause the symptoms. It is also possible that the cause of the disease produces symptoms on the one hand, and tangles and plaques on the other, simply as markers of the disease.

A third change in the brain tissue of patients with Alzheimer's Disease is a major loss of large neurons from the cerebral cortex. In normal aging, while there is no loss from several cranial nerve nuclei, there are decrements in other parts of the brain such as the basal ganglia, cerebellum, cortex and substantia nigra. In Alzheimer's Disease there is an additional loss of thirty-five to forty-five percent of the large neurons in the cortex. Why we lose neurons in this disease, or for that matter in normal aging, is a major question; because this disease is caused by the loss or degeneration of cells. It is not caused by losing one's memory; that's the effect.

There seem to be seven possible general causes for cell loss. One suggestion is genetics, and we know that there is a genetic factor involved in many of the Alzheimer patients: there are some familial cases, and there are Down's patients, those with the extra twenty-first chromosome. There might be a missing trophic factor. That is a factor, a chemical, which is made by one part of the brain and is essential to the survival of another part of the brain. Its being missing is not really a cause, though, because then one would ask what goes wrong with the first part of the brain. Then there is the possibility of the brain becoming immune to some part of itself or some other part of the body, a process called auto-immunity. This is a popular idea, but there is no real evidence for it in regard to Alzheimer's Disease. A normal, continuing process of peroxidation goes on as we age. It results in the yellow pigment we call lipofuscin, and this has been suggested as a major cause of Alzheimer's Disease and various other problems—even of aging itself. But since trees age, and they don't have lipofuscin, and since parts of the brain without lipofuscin also age, and since in Alzheimer's Disease there is no more of this pigment than in normal aged controls, I can't believe that it is important. How about an endogenous toxin (a toxin which is made by the body itself)? Well, it's not impossible that the cost of our having become multi-cellular organisms eons ago causes us to age. Single-celled organisms don't get old, they simply divide and go on. However, as soon as two cell types get together, each cell type having its own metabolism, it becomes conceivable that the normal products of metabolism from one cell type are detrimental to the long term survival of the other cell type. It is an interesting idea, but I don't have any evidence for it. In terms of an exogenous toxin, several people have suggested aluminum. It became very popular following our chance discovery of the model in rabbits. It was then found that aluminum is increased in the brain tissue of some patients with Alzheimer's Disease. But, in Lexington, Kentucky, where the aluminum levels in water are very low because they don't use alum to purify the water, the patients with Alzheimer's Disease come to autopsy and their aluminum concentrations are normal. And so, very possibly, up in Toronto, where the original high levels were found, or in Burlington, Vermont, where they were confirmed, and where they use alum to purify the water, the aluminum is aggregated in the brain simply as a secondary phenomenon rather than as a causal factor. Virus has been blamed for a great many things. We don't know that there is a virus involved; we haven't seen it, nor have we been able to demonstrate any other direct evidence of it at all.

However, a major series of breakthroughs in Alzheimer's Disease in regard to neurotransmitters, the chemicals which send the messages, began in about 1976. Curiously enough, it began almost simultaneously in three laboratories in Great Britain. One finding is a decrease in somatostatin, which is a neuro-modulator peptide. An even more important discovery was that there is a major deficiency of acetylcholine, which is a very important transmitter. This was first published by Peter Davies, who is now working with us in the Bronx. The point of this is that having demonstrated the deficiency of this particular chemical transmitter, there are possible ways of correcting it. The ways are somewhat analogous to those of correcting Parkinson's disease, and they offer the same partial, not total, hope.

I want to close by emphasizing that in the last ten or twenty years there has been very real and significant progress in regard to understanding the nature of Alzheimer's Disease, especially in terms of its mechanism. This gives us real hope and real expectation that within the quite near future we will be able to interrupt the course, to alleviate and to stabilize the disease to some extent. In terms of getting at the ultimate cause of this disease, we've made a lot less progress. On the other hand, the curve of our progress is such that I can't help but be optimistic; and, by nature, pathologists are not optimistic. In Alzheimer's Disease, this one is.

The Clinical Syndrome

by Barry Reisberg, M.D.
Clinical Director and
Senior Research Psychiatrist
Geriatric Study and Treatment Program
New York Medical Center
Panelist

Acknowledgement: This work was supported in part by grant AG 03051 from the National Institute on Aging.

The earliest recognition of the clinical symptomatology associated with what we now term senile dementia of the Alzheimer's type (SDAT), or in the modern psychiatric nomenclature, primary degenerative dementia,[1] appears to have come not from the medical profession, but rather from the legal profession. Solon, in circa 500 B.C., listed impaired judgment resulting from old age as one condition in which a will might be found to be invalid.[2,3] Plato (428/427-348/347 B.C.), in a work completed toward the end of a long and productive life,[4] also recognized the syndrome in stating that, "the commission of certain crimes (sacrilege, treachery, treason) is excusable in a state of madness or when affected by disease or under the influence of extreme old age or in a fit of childish wantonness."[3,5]

Hippocrates, a contemporary of Plato, did not include either dementia, nor the specific dementia associated with the aging process, in his list of mental disorders. The earliest recognition of dementia as a medical entity appears to come to us from a work known as "De Medicina," published by Aureleius Cornelius Celsus, a Roman writer, in the first century A.D.[6-8] Cicero, a contemporary of Celsus, noted in a famous geriatric composition known as "De Senectute" that, "as wantonness and licentiousness are faults of the young rather than of the old, yet not of all young men but only of the depraved, so the senile folly called dotage is characteristic not of all old men but only of the frivolous."[9] However, the first physician to have clearly recognized old age as a cause of dementia was probably Galen (c.A.D. 130–c.A.D. 200). He defined morosis (dementia) as "some in whom the knowledge of letters and other arts are totally obliterated, indeed they can't even remember their own names... Even now it is seen that on account of extreme debility in old age, some are afflicted with similar symptoms."[3,10]

The clinical description of SDAT does not appear to have advanced for more than 15 centuries after Galen, although Galenic traditions were maintained throughout the centuries. In 1793, Benjamin Rush, the founder of American psychiatry and a signer of the American Declaration of Independence, published the first accurate case history of what was to subsequently become known as Alzheimer's Disease or SDAT. He noted that:

> "It would be sufficiently humbling to human nature if our bodies exhibited in old age the marks only of a second childhood, but human weakness descends still lower. I met with an instance of a woman between 80 and 90 who exhibited the marks of a second infancy, by such a total decay of her mental faculties as to lose all consciousness in discharging her alvine and urinary excretions. In this state of the body, a disposition to sleep succeeds the wakefulness of the first stages of old age."[11]

Esquirol, in Paris, defined "demence senile" in an 1838 textbook of psychiatry, in terms with which present day investigators would not quarrel. He stated correctly that this was a condition in which there occurs a weakening of the memory for recent experiences and a loss of drive and willpower. Accurately, he noted that the condition appears gradually and may be accompanied by emotional disturbances.[12]

At the same time that clinical descriptions of SDAT were being advanced, the pathologic syndrome was being elucidated for the first time. Baille described dilatation of the cerebral ventricles in 1795,[13] and Wilks described cortical atrophy and sulcal dilatation in 1864.[14] The so-called pathologic hallmarks of the illness, senile plaques, neurofibrillary tangles, and granulovacuolar degeneration, were described by Redlich in 1898,[15] Alzheimer in 1907,[16] and Simchowitz in 1911,[17] respectively.

Alzheimer described neurofibrillary changes, consisting of tangles of thick argentophilic fibrils within the cytoplasm of neurons, in a woman who first manifested signs of disease at 51 years of age. The term "presenile dementia" had been introduced by Binswanger in 1898.[7] Alzheimer mistakenly believed the neuropathologic changes which he described occurred exclusively in dementia with onset in the presenium (i.e., before 65 years of age). Alois Alzheimer was a faculty member in the department of the eminent German psychiatrist, Emil Kraepelin. Indeed, in 1903, when Kraepelin left Heidelberg to take the chair of the Department of Psychiatry in Munich, Alzheimer accompanied him. It was Kraepelin who began the tradition of applying Alzheimer's name to the presenile form of the disease,[18] a tradition which continued until the 1970's.

In a certain sense, Alois Alzheimer set back scientific knowledge of dementing illness of later life, at the same time that he advanced conceptualizations in other areas with respect to this disease. He mistakenly believed all dementia with onset after age 65 was characterized by the absence of senile plaques or neurofibrillary changes. He also mistakenly attributed the origins of the great majority of cases of dementia with senile onset to cerebrovascular disease. Finally, he mistakenly believed that neurofibrillary changes and senile plaques would not be found to be present in the brains of normal elderly persons.[19]

Gradually, over the next sixty years, these misconceptions were remedied. Subsequent investigations demonstrated that the neurofibrillary tangles first described by Alois Alzheimer, occurred in dementia of senile onset as well as in elderly individuals without dementia.[20-23] Other studies demonstrated the same degree of arteriosclerotic brain changes in elderly persons who were not demented at the time of their demise as in those who were.[24,25] Finally, some revolutionary investigations demonstrated that the presence of senile plaques and of neurofibrillary changes in the brain of elderly persons correlated strongly with dementing illness in later life.[26] These findings led to the realization that Alzheimer's Disease, whether it occurs in the presenium or in later life, was a single illness and that this illness, not arteriosclerosis, was the major cause of late life dementia.[27] Epidemiologic studies had revealed that the dimensions of this illness in terms of morbidity and mortality were such as to make the condition a major area for medical concern, comparable to such other major illnesses as heart disease, cancer, and stroke.[28-35]

Although the medical research community recognized the medical and social implications of these findings in the 1970s, and a series of edited volumes [36-41] and one single authored text[42] were published consolidating knowledge in the field, the condition continued to be neglected in general medical texts. For example, a standardized American textbook of medicine in 1982 devoted only one of its 2,354 pages to Alzheimer's Disease, which it accurately described as "*a major public health problem*... approximately 5% of the population at 65 and up to 20% of the population over 80 are affected"[43] (emphasis added). Neglect in specialty textbooks, specifically psychiatry and neurology, has been equally egregarious.[44,45] Hence, the lay community came to learn about Alzheimer's Disease at approximately the same time as the general medical community.[46,47] Lay recognition was rapidly followed by political recognition of what seems to be a major health problem.[48]

Until very recently these increases in medical and lay understanding with respect to the pathophysiologic nature of Alzheimer's Disease were not accompanied by improved clinical understanding of the disorder. Indeed, a consensus conference, the proceedings of which were published in 1981,[49] demonstrated that medical and scientific understanding of the clinical syndrome, in terms of phenomenology, progression, and prognosis, had not advanced notably since the descriptions of Rush[11] and Esquirol.[12] In this decade, however, the clinical manifestations of the illness have begun to be described in detail. The first detailed case histories of SDAT in its early, middle, and late stages were published in 1981.[48] The stages of the illness process in terms of their clinical manifestations were described in 1982.[49] The implications of the clinical, stage specific, descriptions of normal aging and progressive SDAT (PDD), in terms of the differential diagnosis of the major dementing disorders of the senium, were also described in 1982.[50] Guidelines for physicians on the management of the illness process as it progresses were also published that year.[51] Concordant, ordinal clinical changes on a variety of clinical parameters accompanying each stage of the illness process were described and validated in 1983.[52, 53] At the same time, preliminary prognostic concomitants of specific stages in the illness process were described.[54] Hence, in the past few years we have learned a comparatively enormous amount about the clinical syndrome of SDAT. Formerly, physicians diagnosed the illness strictly in terms of "what it was not," i.e., in medical terminology, it was a diagnosis of exclusion." Presently, it is possible for physicians to diagnose this illness in the same fashion as all other illnesses, i.e., in terms of the unique onset, course, and presentation of the condition in its various stages, as it evolves. It is this unique process which we shall summarize in the remainder of this chapter.

Global Clinical Symptomatology

The clinical symptomatology of persons with cognitive decline consistent with normal aging or Alzheimer's Disease varies depending upon the magnitude or "stage" of cognitive impairment. Within each stage, symptomatology is fairly consistent. The global clinical characteristics of each stage of cognition in normal aged and in those with mild to severe Alzheimer's Disease can be seen in the Global Deterioration Scale for age-associated cognitive decline and Alzheimer's Disease which is described in Table 1.

Previous investigations have revealed strong, significant relationships between progressive decline on these global clinical parameters and in independent psychiatric,[49, 55] neuroradiologic,[56-59] neurometabolic[58-61] and neuroimmunologic[62] assessments in subjects with normal aging and progressive SDAT.

Many aged individuals have neither demonstrable nor subjective cognitive impairment (Stage 1). Others, perhaps constituting a majority of the aged, suffer varying degrees of impairment which are best conceptualized within three broad clinical phases, although six additional distinct clinical stages (and a total of 15 functional stages) are potentially distinguishable. The condition is sufficiently widespread such that professionals will readily recognize the clinical syndromes constituting each of these phases, both from experiences with elderly patients, as well as from experience in one's own life with family members.

Normal Aging

The earliest phase has been termed the *Forgetfulness Phase*. In this phase the deficit is primarily subjective although it may be objectified utilizing detailed psychometric testing.[63] The individual, and frequently his or her spouse as well, recognize increased difficulty recalling names of places and objects which had formerly been familiar. They also frequently notice an increased tendency to forget where objects have been placed. The Forgetfulness Phase individual remains as capable of functioning in social and employment situations as formerly. Nevertheless, the subjective symptomatology is accompanied by an increased sense of concern both on the part of the patient and the spouse, as well as increased irritability and a slight feeling of "shame" on the part of the patient. There is also a mutually identifiable mild increase in strain on the family relationship. Although the onset of these symptoms is met with a sense of appropriate concern, there is no sense of helplessness on the part of the patient or the spouse.[64]

The precise incidence of Forgetfulness Phase Symptomatology in elderly persons is unknown at the present time. However, these symptoms do appear to be quite common. In one pilot survey, it was estimated that over 80% (90 of 111) of elderly, community residing men, with "normal" mood and cognitive function, had memory complaints of varying severity and duration.[65] Although Forgetfulness Phase symptomatology is widespread, there is accumulating evidence that persons with this disorder are distinct behaviorally,[50, 63] emotionally[64] and physiologically[62] from persons of the same age who do not suffer from complaints of cognitive decline. Kral has proposed the terminology Benign Senescent Forgetfulness, to designate this condition.[66] Implicit in Kral's nomenclature, is the hypothesis that the great majority of persons with these symptoms do not suffer any further decline in cognitive capacities. Results from follow-up studies support this hypothesis. In one study, Reisberg, et al.[54] followed 16 community residing persons (mean age 68.70 ± 4.05 years) with subjective and psychometrically verified cognitive symptomatology as described above, for a mean interval of 27.18 ± 3.71 months) (see Table 2). At the time of follow-up the investigators found that none of the individuals had measurably worsened cognitively, and all continued to be alive and well and community residing (see Tables 2 and 3).

Analogous results have been reported by Kral in a somewhat older patient group.[67] He followed 94 subjects with a mean age of 80.5 years of whom 40 subjects had clinically preserved memory function and 20 had Senescent Forgetfulness over a four-year observation period. He found no significant difference in the death rate between the subjects with preserved memory and those with Senescent Forgetfulness. However, both groups survived significantly longer than the 34 subjects from the more severly impaired cohort. Furthermore, over the 4-year observation period, only one of Kral's 20 Senescent Forgetfulness patients became more severely cognitively impaired and required subsequent institutionalization.

Early Alzheimer's Disease

In a minority of individuals, Forgetfulness symptomatology does presage a more overt phase of cognitive deterioration, which has been termed the *Confusional Phase*. This phase begins at the point at which cognitive deficit becomes identifiable in the course of a detailed clinical interview. Individuals in this phase can no longer function as well in demanding employment or social situations as formerly. The deficit in recalling names becomes more manifest, such that familiar clients' and students' names are not easily recalled. The increased deficit in locating where objects have been placed results in the loss or temporary misplacement of valuables. Other cognitive deficits also become notable, particularly deficits in the recall of recent events and activities in which the patient had participated. Deficits in the recall of personal history and past events also occur, but are more difficult to demonstrate clinically. Concentration deficits, however, are frequently readily elicited utilizing such common clinical assessments as serial subtractions. Deficits in daily functioning also become manifest in this phase. The earliest clear-cut symptom recalled by family members is frequently an episode in which the patient had gotten hopelessly lost when traveling to a location which should have been reached without undue difficulty. As deficits become more manifest, Confusional Phase patients become less capable in managing their financial affairs.

A sense of helplessness on the part of both patients and those closest to them develops in this phase. Their sense of helplessness appears to replace the slight irritability, shame, and increased familial strain which had accompanied the onset of symptomatology in the earlier phase. Persons in the Confusional Phase also develop what psychiatrists term a "flattening of affect." That is to say, persons in this phase become emotionally less responsive than previously. In part, this occurs as a result of the increased feelings of helplessness. However, the decreased emotional responsivity is also a product of the confused patient's decreased ability to process or understand incoming stimuli. The adaptive response to these decremental abilities is a partial withdrawal from stimulus input, and a lower level of cognitive and emotional responsiveness to events around them.

Surveys have indicated that the prevalence of Confusional Phase symptomatology (also referred to as mild dementia) is 10 to 12 percent of all persons aged 65 and greater.[68] On the basis of these figures, we might expect that in the United States, approximately 3 million persons suffer from Confusional Phase symptomatology. Although the natural history of Confusional Phase symptomatology has not been extensively studied, in most Late Confusional patients these symptoms do appear to herald more malignant symptomatology, with further decline, institutionalization, and not infrequently, death within the subsequent two to five-year period. Of 11 patients (mean age 72.82 ± 5.95 years) with Late Confusional Phase (stage 4) symptomatology followed by Reisberg, et al.[54] over a period of 27.54 ± 5.18 months, three were deceased or institutionalized at the time

Table I

Global Deterioration Scale (GDS) for Age-Associated Cognitive Decline and Alzheimer's Disease*

GDS stage	Clinical phase	Clinical characteristics
1 No cognitive decline	Normal	No subjective complaints of memory deficit. No memory deficit evident on clinical interview.
2 Very mild cognitive decline	Forgetfulness	Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.
3 Mild cognitive decline	Early Confusional	Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit become evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview conducted by a trained geriatric psychiatrist. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.
4 Moderate cognitive decline	Late Confusional	Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of one's personal history; (c) concentration deficit elicited on serial substractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and person; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations occur.
5 Moderately severe decline	Early dementia	Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives: e.g., their address or telephone number of many years, the names of close members of their family (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses and children's names. They require no assistance with toileting or eating, but may have some difficulty choosing the proper clothing to wear and may occasionally clothe themselves improperly (e.g., put shoes on the wrong feet, etc.).
6 Severe cognitive decline	Middle dementia	May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will display ability to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor; may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activites; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e., loss of willpower becuase an individual cannot carry a thought long enough to determine a purposeful course of action.
7 Very severe cognitive decline	Late dementia	All verbal abilities are lost. Frequently there is no speech at all—only grunting. Incontinent of urine; requires assistance toileting and feeding. Lose basic psychomotor skills, e.g., ability to walk. The brain appears to no longer be able to tell the body what to do. Generalized and cortical neurologic signs and symptoms are frequently present.

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*Reisberg, B., Ferris, S.H., de Leon, M.J., and Crook, T., *Am. J. Psychiatry,* 139:1136-1139, 1982.

Table 2

Follow-Up Intervals, Residential Status at Follow-Up, and Mortality Differentiated by Initial GDS Scores*

GDS (Initial Assessment)	Follow-Up Interval (months) Mean ± S.D.	Range	Residential Status at Follow-Up and Mortality
2	27.18±3.71	23–33	16 Community Residing 0 Deceased 0 Institutionalized
3	27.36±5.46	18–34	14 Community Residing 0 Deceased 0 Institutionalized
4	27.54±5.18	21–37	8 Community Residing 2 Deceased 1 Institutionalized†
5	23.17±5.78	16–32	3 Community Residing 1 Deceased 2 Institutionalized†
Total	26.81±4.94	16–37	41 Community Residing 3 Deceased 3 Institutionalized†

*From Reisberg B, Shulman E, Ferris SH, de Leon MJ and Geibel V: Clinical assessments of age-associated cognitive decline and primary degenerative dementia: Prognostic concomitants. *Psychopharmacology Bulletin*, 19:734–739, 1983.

†In nursing homes.

Table 3

Initial and Follow-Up Scores on Assessment Parameters (Mean ± S.D.) for Community Residing Survivors[1]

		MSQ Score		Clinical Cognition Assessment Scores		Functional Assessment Inventory Scores	
GDS	N	Pre	Post	Pre	Post	Pre	Post
2	16	.25± .45	.13± .34	12.94±1.44	13.19±2.61	6.00± .00	6.37±0.72
3	14	.64±1.08	1.36±1.08	14.71±2.64	15.71±2.89**	6.21±0.58	7.36±1.65
4	8†	3.00±2.20	5.87±1.73*	16.50±3.21	22.13±2.47**	9.25±2.05	13.83±2.51
5	3†	7.33±2.08	8.33±0.58	18.66±3.79	19.33±2.52	12.66±1.53	16.00±1.73
Total	41†	1.41±2.31	2.27±2.98**	14.63±2.96	16.42±4.21***	7.54±2.85	8.90±3.82***

*P≦05 Significance of Baseline vs. Follow-Up Differences on Assessment Measures: Wilcoxin Matched
**P≦01 Pair Signed Rank Test (from Colton, *Statistics in Medicine*, 1974). Non-parametric, two-tailed probabilities.
***P≦001

† Community residing survivors only.

[1] Reisberg B, Shulman E, Ferris SH, de Leon MJ and Geibel V: Clinical assessments of age-associated cognitive decline and primary degenerative dementia: Prognostic concomitants. *Psychopharmacology Bulletin*, 19:734–739, 1983.

of follow-up (Table 2). Of the remaining eight individuals, all continued to function in a community setting. Of these, 50% evidenced significant decline over the follow-up period, and 50% were not notably worse in either cognition or functional capacity (Table 3). Each of the 11 patients followed in the Late Confusional Phase demonstrated at least some decline, however (even if not overtly manifest decline), on detailed cognizance parameters. Hence, this phase (stage 4) can be said to represent the earliest stage of true Alzheimer's Disease, in which, by definition, gradual cognitive decline is a concomitant of the illness process.

The Early Confusional Phase (stage 3) actually represents a borderland between normal aging, with characteristic Forgetfulness Phase symptomatology of normal aging, and true Alzheimer's Disease. Fourteen patients (mean age 68.71 ± 5.25 years) with Early Confusional Phase symptomatology followed by Reisberg et al.[54] over a period of 27.36 ± 5.46 months, showed significantly greater decline as a group than the Forgetfulness Phase subjects over the same time period (Table 3). However, only about half of these 14 subjects demonstrated any decline whatever over the follow-up period, and all 14 Early Confusional Phase subjects remained alive and well and community-residing at the time of follow-up (Table 2).

Middle and Late Stage Alzheimer's Disease

The *Dementia Phase* can be defined as beginning at the point at which patients can no longer survive if left on their own. Difficulties in functioning and in carrying out basic activities of daily living are the hallmark of this phase of cognitive impairment. Early in this phase (stage 5), patients frequently have difficulty in choosing the proper clothing. At this point, individuals are forced to severely circumscribe their movements and activities. Travel, even to familiar neighborhood locations, becomes difficult, if not impossible. Financial affairs are taken over by the spouse, caretaker or other family members. Memory suffers to the extent that patients have difficulty recalling the name of the current President, the year, their address, or their current location. Patients also forget the names of schools which they have attended, and towns and cities in which they have lived.

As the Dementia Phase progresses (stages 6 and 7), deficits develop in all cognitive and functional areas. The ability to cut food for oneself is lost, and, ultimately, the ability to manipulate silverware disappears in entirety. Patients lose the ability to wash and bathe themselves, even with adequate assistance. Patients become incontinent, and, ultimately, require assistance in toileting themselves. Patients become unsteady in their movements and, ultimately, psychomotor abilities are lost to the extent that individuals can no longer ambulate. All recent and remote memories and cognitive capacities gradually disappear. Patients forget the names of the spouse upon whom they are entirely dependent for survival, and, subsequently, lose the ability to even recognize their own name. All self-identity is lost. The previous profession of a lifetime is entirely forgotten as are all events from one's past. Calculating and concentrating ability is lost to the extent to which individuals cannot count from one to five consecutively. Ultimately, all ability to speak is lost; patients can only stare blankly and grunt.

The loss of one's cognitive and intellectual capacities is too overwhelming a deficit for conscious comtemplation. Consequently, individuals in the Dementia Phase deny much of their deficit. For instance, a patient may aver that he cannot recall the current President's name because he "doesn't follow politics," or his residence of twenty years because "I've only recently moved." Emotional difficulties, which become manifest in this phase, are also frequently denied. The onset of symptomatology in this phase is met by an acute sense of shame. This is replaced by marked irritability and agitation as the condition progresses. Psychiatric manifestations with suspiciousness, overt paranoia, delusions, and visual, or other hallucinatory experiences, frequently occur in the middle to late Dementia Phase. These symptoms make caring for the patient particularly difficult and force even the most heroically concerned family to confront the necessity of institutionalization.

Estimates have indicated that Dementia Phase cognitive deficit occurs in approximately 5% of persons aged 65 and greater.[68] Hence, more than one million Americans are probably afflicted with this condition. Government studies indicate that chronic cognitive deficits, probably synonymous in most cases with the condition which we are describing, occur in 58% of the more than one million Americans in nursing homes.[69] Many such patients are also housed in other institutional facilities such as state mental hospitals and veterans hospitals. More than half of the patients over 65 in state and county mental hospitals carry diagnoses compatible with chronic cognitive decline. Despite these dramatic statistics, it is thought that at least half of all patients in the Dementia Phase remain within the community where they are assisted by their spouses, siblings, children, or others.

The Dementia symptoms described are associated with a marked decrease in life expectancy. In one study, the mean survival period was 2.6 years for men and 2.3 years for women, in comparison with 8.7 years and 10.9 years, respectively, for age-matched, nondemented controls.[12] Of 6 community residing individuals with early Dementia Phase symptomatology (mean age 74.2 ± 4.7 years) who Reisberg, et al.[54] followed for a mean interval of 23.17 ± 5.78 months, 1 was deceased at follow-up, 2 were institutionalized at the time of follow-up, and 3 remained community residing and performed only slightly, and not significantly worse on a brief Mental Status Questionnaire Assessment (Tables 2 and 3).

It is important for clinicians to recognize that the prognostic concomitants of the stages in the evolution of progressive cognitive decline vary. However, if the patient has been correctly diagnosed, then the presence of a particular stage of cognitive impairment does imply that the patient must have previously experienced the preceding stages and symptoms. In all cases, the progress of the condition is gradual, and all patients who are correctly diagnosed and who are not the victims of secondary disease processes spend periods of several months to years in each global stage.

Multi-Axial Clinical Assessments

More recent work has indicated that these global stages can also be clinically subdivided into five clinical axes: (I) Concentration; (II) Recent Memory; (III) Past Memory; (IV) Orientation; and (V) Functioning and Self-Care. When properly defined, decline on each of these clinical parameters tends to proceed at a rate consistent with the global stage of cognitive functioning.[52, 70] Definitions of these clinical parameters, or "axes," corresponding to the successive stages of global cognitive deterioration can be seen in the Brief Cognitive Rating Scale described in Table 4.

Since scores on each of the clinical axes described in Table 4 correlate strongly not only with each other, but also with the corresponding Global Deterioration Scale (GDS) scores (Table 1), the Brief Cognitive Rating Scale (BCRS) axes (Table 4) provide a brief clinical sketch of the corresponding clinical stage of cognitive functioning. Hence, a patient with moderate cognitive decline in the Late Confusional Phase (GDS 4), as described in Table 1, is likely to show a corresponding degree of impairment on each of the BCRS axes. Specifically, this patient is likely to demonstrate "definite concentration deficit for persons of their background" (Table 2, Axis 1, a score of "4"). This concentration deficit can frequently be manifested by asking the patient to subtract serial 7's from 100. Not only will these Late Confusional Phase patients frequently demonstrate marked deficits on substraction of serial 7's, but frequently deficits in subtraction of serial 4's from 40 as well. As can be seen in Table 2, these same patients are, however, likely to be capable of subtracting serial 2's from 20 without difficulty.

Patients in the Late Confusional Phase are also likely to be unable to recall certain major events from the previous weekend or week and to have a "scanty knowledge of current events" (Axis II, rating score "4"). However, Late Confusional Phase patients are likely to be able to recall the name of the current President or Head of State of the country in which they reside, and to recall correctly their current address.

As can be seen in Table 4, the Late Confusional Phase patient is likely to show corresponding deficits in past memory (Axis III), as well. A common statement with respect to mildly to moderately impaired PDD patients, frequently articulated by both the patients themselves as well as family members, is that their recent memory has suffered, however the patients' past memory "remains excellent." This perception is, in part, a product of the PDD patient's continual necessity to recall events from his recent past, whereas he is rarely

Table 4

Brief Cognitive Rating Scale (BCRS)*

Axis	Rating	Item
Axis I:	(Circle Highest Score)	
Concentration and Calculating Ability	1	No objective or subjective evidence of deficit in concentration.
	2	Subjective decrement in concentration ability.
	3	Minor objective signs of poor concentration (e.g. on subtraction of serial 7s from 100).
	4	Definite concentration deficit for persons of their background (e.g. marked deficit on serial 7s: frequent deficit in subtraction of serial 4s from 40).
	5	Marked concentration deficit (e.g., giving months backwards or serial 2s from 20).
	6	Forgets the concentration task. Frequently begins to count forward when asked to count backwards from 10 by 1s.
	7	Marked difficulty counting forward to 10 by 1s.
Axis II: Recent Memory	1	No objective or subjective evidence of deficit in recent memory.
	2	Subjective impairment only (e.g., forgetting names more than formerly).
	3	Deficit in recall of specific events evident upon detailed questioning. No deficit in the recall of major recent events.
	4	Cannot recall major events of previous weekend or week. Scanty knowledge (not detailed) of current events, favorite TV shows, etc.
	5	Unsure of weather; may not know current president or current address.
	6	Occasional knowledge of some recent events. Little or no idea of current address, weather, etc.
	7	No knowledge of any recent events.
Axis III: Past Memory	1	No subjective or objective impairment in past memory.
	2	Subjective impairment only. Can recall two or more primary school teachers.
	3	Some gaps in past memory upon detailed questioning. Able to recall at least one childhood teacher and/or one childhood friend.
	4	Clear-cut deficit. The spouse recalls more of the patient's past than the patient. Cannot recall childhood friends and/or teachers but knows the names of most schools attended. Confuses chronology in reciting personal history.
	5	Major past events sometimes not recalled (e.g., names of schools attended).
	6	Some residual memory of past (e.g., may recall country of birth or former occupation).
	7	No memory of past.
Axis IV: Orientation	1	No deficit in memory for time, place, identity of self or others.
	2	Subjective impairment only. Knows time to nearest hour, location.
	3	Any mistake in time—2 hrs; day of week—1 day; date—3 days.
	4	Mistakes in month—10 days or year—one month.
	5	Unsure of month and/or year and/or season; unsure of locale.
	6	No idea of date. Identifies spouse but may not recall name. Knows own name.
	7	Cannot identify spouse. May be unsure of personal identity.
Axis V: Functioning and Self-Care	1	No difficulty, either subjectively or objectively.
	2	Complains of forgetting location of objects. Subjective work difficulties.
	3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations.
	4	Decreased ability to perform complex tasks (e.g. planning dinner for guests, handling finances, marketing, etc.)
	5	Requires assistance in choosing proper clothing.
	6	Requires assistance in feeding, and/or toileting, and/or bathing, and/or dressing.
	7	Requires constant assistance in all activities of daily life.

* by Barry Reisberg, M.D., Gerri E. Schwartz, Ph.D., Thomas Crook, Ph.D., and Steven H. Ferris, Ph.D.,

queried in detail with respect to his childhood or early school experiences. On these unusual occasions when a mildly or moderately impaired PDD patient is required to recall details from his past, he frequently finds it acceptable to retreat to the rationalization, "It was so long ago, how can I be expected to remember that?" Hence, deficits in past memory, although present, are not as readily manifest, and are not as troubling for the patient or his family.

The orientation deficits which are probably manifest at each Global Deterioration Scale stage can be seen in Axis IV of the BCRS. Hence, in the Late Confusional Phase (GDS = 4), the patient is likely to err by 10 or more days in response to queries as to the current date. However, at this stage, the patient most probably can still recall the current year and remains oriented with respect to his or her location.

Functional deficits are particularly notable concomitants of each global stage of deterioration. These deficits are the ones most clearly observed by family members and caretakers of Alzheimer's patients. In the Late Confusional Phase, the characteristic functional deficits are difficulties with handling finances and with marketing. However, these patients not only remain fully capable of *putting on* their clothing properly, but are also capable of *choosing* the proper clothing for the season and any special occasions of the moment.

Other Clinical Features

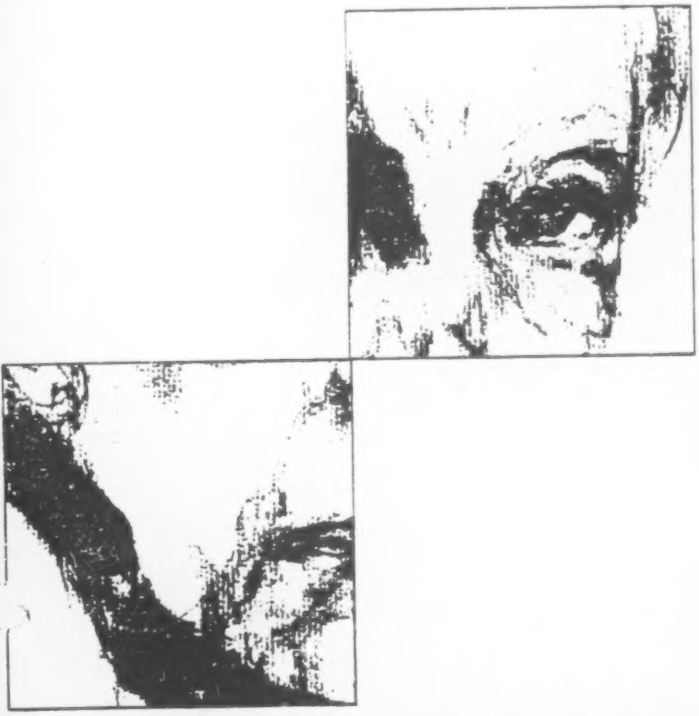
In addition to the clinical features described in Tables 1 and 4, other clinically observable changes also accompany the various stages of progressive cognitive decline. The most notable additional clinical features are those related to speech, to psychomotor abilities, and to mood and behavior (Table 5).

Table 5

Brief Cognitive Rating Scale (BCRS)
Language, Motoric, and Mood Concomitants*

Axis	Rating	Item
Axis VI: Language	1	No subjective or objective speech deficit.
	2	Subjective deficits in recalling names of persons and objects.
	3	Overt word-finding difficulties which may result in intermittent interruptions of speech or mild stuttering.
	4	Decrease of verbalization. Patient becomes more reticent. Alternatively, tendency to ramble.
	5	Overt paucity of spontaneous speech. Sentence production abilities remain intact.
	6	Inability to speak in sentences. Responses tend to be limited to one or a few words.
	7	Verbal abilities are lost. Vocabulary may be limited to one or two words, if any. Patient may repeat words or phrases (verbigeration), or make up new words or phrases (neologisms). Patient's vocabulary may be limited to grunts or screams.
Axis VII: Motoric functioning	1-2	No subjective or objective motor deficits.
	3	Decreased ability in the performance of complex psychomotor tasks such as sailing, or complex constructional tasks.
	4	Gait becomes slowed. The deficit is noticeable to family members familiar with the patient but not necessarily to clinicians who may not know the patient well. Patient becomes more cautious with respect to movements and activities in general, such as driving an automobile.
	5	Slowing of gait and movement is clearly evident, even to strangers. Auto driving ability is compromised or abandoned.
	6	Steps become small and movements are markedly slowed. Difficulty with signing name properly may occur.
	7	Ability to ambulate is lost. Inability to properly grasp a writing instrument.
Axis VIII: Mood and Behavior	1	No subjective or objective changes in mood or behavior.
	2	Subjective increase in anxiety or concern with respect to cognitive functioning.
	3	Overt anxiety evident to clinician and/or patient's family.
	4	Blunting of emotional responses evident to family.
	5	Flattened affect evident to physician. Patient may have crying episodes.
	6	Overt agitation and/or formal thinking disorder (e.g., paranoia, hallucinations, delusions).
	7	Nonverbal agitation alternating with pathologic passivity.

*Reisberg B, London E, Ferris SH, Borenstein J, Scheier L, and de Leon MJ: The Brief Cognitive Rating Scale: Language, motoric, and mood concomitants in primary degenerative dementia. *Psychopharmacology Bulletin*, 19:702-708, 1983.



Changes in Speech and Language

As stated in Table 1, the Forgetfulness Phase is frequently accompanied by subjective difficulty in recalling names of persons and objects. In the Early Confusional Phase more overt word finding difficulties occur and these deficits become evident to spouses and other intimates. Occasionally in this phase, the patient's verbalizations will be interrupted intermittantly as the patient gropes for the proper word. Mild stuttering may also occur on occasion. In the Late Confusional Phase, the language deficit is most frequently manifested in a notable decrease in verbalizations. The patient becomes notably more "quiet" than formerly. The reasons for the Late Confusional Phase patients' unaccustomed reticence are multiple and include decreased intellectual abilities in general, as well as decreased verbal abilities, specifically. The reticence is also compatible with an affective flattening which occurs at this phase. Conversely, some patients react to this increased word finding deficit in the Confusional Phase with a tendency to ramble or "talk around the point." This form of adaptation to the deficit may lead to an overall increase in verbalizations, although the precision of speech is compromised.

In the Early Dementia Phase, the earlier reticence becomes an overt "paucity of speech." Sentence production remains intact, however the patient rarely offers more than single sentence responses to queries. Spontaneous speech is also notably decreased. In the Middle Dementia Phase, the patient is no longer capable of speaking in sentences. Responses tend to be limited to one or, at most, a few words. Patients at this phase who have acquired new languages over the course of their lifetime frequently revert to using words from languages which had been acquired earlier in life. For instance, one man in the Mid-Dementia Phase had been born in Poland, moved to Germany as a child, where he met his wife, and subsequently moved with his wife to the United States, where they resided for the greater portion of their adult lives. This man began speaking to his wife not in their current English tongue, nor in their former mutual language, German, but rather in Polish, which was unintelligible to his wife and others attending the patient.

In the Late Dementia Phase all verbal abilities are lost. Grunting, neologisms, verbigeration, echolalia and other major language disturbances frequently occur at this stage. Some patients simply let out infrequent screams. One patient at this stage had a vocabulary consisting entirely of "okay," which she repeated innumerable times when she recognized a family member, in response to stress or in response to other verbalization-provoking phenomena. Verbigeration is frequently manifested by repetition of the first syllable of a word. At some point in the Late Dementia Phase, most patients eventually lose all verbal abilities.

Changes in Psychomotor Abilities

Decreased abilities in the performance of complex psychomotor tasks, such as sailing ability or complex constructional tasks, do not occur until the Early Confusional Phase. Since these kinds of complex motor abilities are not necessarily a part of modern, everyday life, psychomotor deficits may not be noted either by the patient or by the spouse at this phase. In the Late Confusional Phase, motor abilities do overtly decline. Most frequently those who know the patient will note that the patient's gait has become slowed and that the patient is more "cautious" with respect to movements in general. In the Early Dementia Phase, the slowing of gait and other movements are clearly observable even to a physician unfamiliar with the patient's previous level of functioning. Although arthritis, mild parkinsonism, or other clinical causes of impaired movement may sometimes coexist in these aged patients, the Alzheimer's process alone is sufficient to account for the observed motor changes in the Early Dementia Phase persons. In the Mid-Dementia Phase, the patient frequently requires assistance with ambulation. Even if assistance is not required, the patient's steps become very small and movements markedly slowed. Individuals at this phase also frequently have difficulty signing their name properly, even if some assistance is provided in this task. Another psychomotor manifestation at this phase is increased difficulty in handling silverware. The ability to properly utilize a knife or fork is compromised. In the Late Dementia Phase patients lose all ability to walk. They cannot even begin to sign their names and are frequently unable to grasp, in a usable fashion, a pen or pencil placed in their hand. They cannot utilize utensils and either eat with their hands or must be fed.

Changes in Mood and Behavior

The cognitive changes are accompanied by changes in mood and behavior which also vary with the overall severity of the illness. The mild subjective symptomatology of the forgetfulness phase is accompanied by an increase in "concern" or anxiety in the patient. This anxiety is voiced by the patient (i.e., it is subjective), however, it is not manifest in a clinically overt manner.

In the Early Confusional Phase the stresses and demands of a lifestyle which the patient is no longer capable of successfully fulfilling frequently result in more overt anxiety manifestations. The latter may be evident to the clinician as well as the patient's spouse. In the Late Confusional Phase, denial becomes a dominant mechanism of defense, and the patient frequently begins to adaptively withdraw from stresses. The net effect of these denial and withdrawal processes is a blunting of emotional responses which psychiatrists term a "flattening of affect." The patient becomes less involved in activities—not only intellectually, but also emotionally.

In the Early Dementia Phase this decreased involvement may be accompanied by a mourning process. The patient may suddenly begin to cry for no apparent reason over the course of the day and then just as suddenly stop. Frequently, denial prevents a patient from expressing the reason for their crying episodes. However, in most cases, the patient is probably mourning the loss of his intellect, either consciously or unconsciously. The Mid-Dementia Phase is accompanied by overt agitation. The agitation may result from the constant threat of an environment which the patient can no longer successfully manipulate and which therefore becomes genuinely dangerous. The stresses of the illness, as well as the physiologic changes accompanying the illness, may result in severe psychiatric disturbances at this stage, as well as generalized agitation. Patients may begin "talking to themselves." They may also experience visual hallucinations, which may be related to their reveries. Frequently patients become paranoid or formally delusional. The paranoia may be the result of adaptive suspicion with respect to a world which is becoming frighteningly unfamiliar. The delusions may serve to provide one explanation for the anger or memory deficits which have befallen the patient.

In the Late Dementia Phase, patients become relatively passive as they lose the ability to speak and to walk. Under these circumstances, agitation is utilized for communication. Excitement or crying out may indicate that the patient is about to have a bowel movement and requires assistance. It might also indicate that the patient has soiled himself. Finally, increased respiration, increased verbalization, or a scream may indicate that the patient sees someone whom he knows well.

Functional Staging

Recent work has indicated that functionally, one can distinguish at least 15 distinct ordinal (progressive) stages in the continuum from normal aging to the end stages of Alzheimer's Disease.[70] These stages are described in Table 4, Axis V, and in Table 6. The recognition of these stages represents an enormous advance in our understanding of Alzheimer's Disease since they enable clinicians and scientists to accurately quantify, in a readily comprehensible manner, the precise magnitude of impairment in Alzheimer's Disease much more readily and accurately than previously. It also represents an enormous advance in enabling clinicians to accurately diagnose and differentially diagnose Alzheimer's Disease.

For example, if a patient with cognitive impairment of gradual onset loses the ability to walk (functional stage, 7 c) but the patient is still capable of articulating words, then an etiologic or confounding illness such as CNS neoplastic disease or stroke becomes much more likely to be the origin of the patient's impairment than Alzheimer's Disease. Similarly, patients with so-called "depressive pseudodementia" may lose the ability to dress themselves, but still be capable of choosing the proper clothing to wear. Alzheimer's patients always lose the ability to choose their clothing properly (functional stage 5) before they lose the ability to put on their clothing properly (functional stage 6 a). Hence, the ordinal progression of functional loss in normal aging and SDAT provides a particularly useful tool for both the diagnosis and differential diagnosis of the age-associated cognitive disorders.

Insight and Denial

A complex pattern of increased concern, anxiety, and denial of deficit, which is stage specific, accompanies the evolution of progressive cognitive deficits. An understanding of this process is necessary for the proper assessment and clinical differential diagnosis of early age-related memory loss and Alzheimer's Disease.

"Denial" has been defined as a "defense mechanism, operating unconsciously, used to resolve emotional conflict and allay anxiety by disavowing thoughts, feelings, wishes, needs, or external reality factors that are consciously intolerable."[71] Denial is generally betrayed by an obvious disparity between the condition of the patient and how he reports it. Such patients often smilingly insist that all is well or that a symptom does not exist.[72] Although denial has been reported as a concomitant of a very broad spectrum of physical and emotional maladies, the extent to which this mechanism operates as a concomitant of cognitive decline in normal aging and in Primary Degenerative Dementia apparently has only recently been systematically studied.[64]

The loss of one's intellectual and general thinking capacities is a terrible tragedy, too painful for conscious contemplation. As with any devastating illness or loss, the psychological mechanism of defense termed denial operates to prevent fully conscious contemplation of the loss, which would be emotionally overwhelming.

The earliest symptoms of cognitive decline in what we term the Forgetfulness Phase are fully recognized by patients and by those with whom they are in most intimate contact, their spouses. In a sense, the observational powers of the spouse are validated by the remarkable concordance of both patients and their spouses with respect to the onset and severity of these very subtle early cognitive symptoms. Emotionally, these early symptoms evoke a sense of alarm on the part of both patients and their spouses. Both recognize increased emotional difficulties which noticeably affect their family relationship. Both patients and their spouses become somewhat more irritable as a result of these symptoms. The spouses, in particular, are somewhat ashamed of the patients' forgetfulness; however, neither the patients nor their spouses feel at all helpless at this early stage. Interestingly, at this early stage, patients become not only acutely aware of a cognitive problem in themselves, but also acutely, or perhaps hyperacutely, sensitive to slight cognitive problems in their spouses.

In general, the patients' reported awareness of their memory deficits tends to peak in the Confusional Phase. Spouses' awareness of memory problems in the patient tends not to differ markedly from the patients' assessments at this phase. Patients and their spouses continue to experience some emotional problems as a result of the patients' memory difficulties. However, increased irritability and shame are transient phenomena which the patient is able to suppress at this phase. A sense of helplessness on the part of both the patient and the spouse also develops for the first time in this phase. Confusional Phase patients and their spouses appear to be capable of adjusting socially to the patients' memory problems and isolating the cognitive symptomatology somewhat in terms of its marital and social manifestations. Denial of specific cognitive problems does occur in the Confusional Phase, however. Specifically, patients, but not their spouses, are unwilling to accept that they might be less capable of carrying out their basic activities of daily living than previously.

In the Dementia Phase, patients develop a profound denial of cognitive and emotional deficit. The denial appears to occur in precisely those areas of cognition and emotional functioning which are most severely affected. Despite the profound denial, even in the Early and Mid-Dementia Phases, patients do appear to display insight with respect to the functioning of their spouses in cognitive and other areas.

Clinically, the denial of cognitive deficit which appears to be such a notable concomitant of Dementia Phase symptomatology manifests itself in various ways. Although they are a minority, some patients find any evaluation of their memory which forces them to begin to confront their deficit too painful an experience for voluntary participation. Some patients refuse to see physicians in general, and physicians or other professionals who will be evaluating their cognitive status in particular. Other patients who are brought in for an evaluation become acutely anxious. They may develop an actual anxiety attack or exhibit conversion or dissociative symptomatology. For example, one woman recently responded to all questions which were put to her by panting and grunting. Other patients simply refuse any evaluation of their memories and leave the office or testing room.

Many other Dementia Phase patients, although they display marked denial symptomatology, do not exhibit the extreme symptoms described above. For example, a typical patient when asked "Who is the President of the United States?" will simply respond with the rationalization, "I don't follow politics very closely." Other rationalizations are also very frequent. A Dementia Phase patient who does not recall the name of the college where he earned his degree might explain, "But that was so many years ago, how can you expect me to remember what school I went to 50 years ago?"

Collectively, these rationalizations and other defense mechanisms buttress the Dementia Phase patients' capacity for denial. The net gain for the patients is the psychological defense which they develop against what would otherwise be very traumatic emotional concomitants of their illness process.

Differential Diagnosis

The prognostic data can be utilized to provide us with a definition of the clinical boundaries between Primary Degenerative Dementia, consistent with Alzheimer's Disease, and age-associated cognitive decline, consistent with normal aging. Clearly, the Forgetfulness Phase is benign and does not fit the definition of a degenerative, slowly progressive condition. Equally clearly, the Late Confusional Phase, with more severe symptomatology, is consistent with a progressive degenerative condition. Early Confusional Phase symptomatology is less prognostically clear-cut, and hence, provides a "borderline" condition midway between "benign senescent forgetfulness" and a degenerative illness consistent with Alzheimer's Disease.

When patients do succumb to Alzheimer's Disease, they generally develop a secondary infection or illness which is the result of their diminished capacity to care for themselves. Pneumonia, secondary to aspiration or exposure, is one of the most frequent immediate causes of death. Infected decubital ulcerations are another frequent cause of mortality. Although it has been said that patients do not die of Alzheimer's Disease directly, this hypothesis is not entirely consistent with clinical experience. Some patients, as progressive brain decay proceeds, become comatose and eventually die in this state. The coma may be preceded by a mild febrile state, however a specific infectious etiology or locus is not always found, even if a complete medical work-up is performed. It is conceivable that diminished hypothalamic function, as well as decreased cortical capacity, are related to this terminal malignant process.

As stated in the introduction to this chapter, the real key to the diagnosis and differential diagnosis of age-associated cognitive decline, consistent with normal aging, and of Alzheimer's Disease from other clinical conditions with which they are commonly confused, is recognition of the characteristic clinical features of the progression of this illness process. These characteristic features have been described briefly in this chapter. Additional salient features in the clinical differential diagnosis of these disorders from conditions with which they are commonly confused can be seen in Table 7.

Conclusion

Alzheimer's Disease, an ancient problem, has been recognized since antiquity. The rudiments of accurate clinical descriptions of the disorder do not appear before the late 18th and early 19th century. Only in the past three years has this syndrome been described in detail. This newfound knowledge represents an enormous advance in our understanding of Alzheimer's Disease. In many ways, the clinical syndrome of Alzheimer's Disease is a very "recent discovery."

Table 6

Functional Staging of Severe Alzheimer's Disease*
GDS 6-7

6 (a) Difficulty putting on clothing properly
  (b) Unable to bathe without assistance; may develop fear of bathing
  (c) Inability to handle mechanics of toileting
  (d) Urinary incontinence
  (e) Fecal incontinence

7 (a) Ability to speak limited to one to five words
  (b) All intelligible vocabulary lost
  (c) All motoric abilities lost
  (d) Stuporous
  (e) Comatose

* Reisberg B, Ferris SH, Anand R, de Leon MJ, Schneck MK, and Crook T: Clinical assessment of cognitive decline in normal aging and primary degenerative dementia: Concordant ordinal measures. In *Proceedings, VII World Congress of Psychiatry*, Plenum, in press.

Table 7

Differential Diagnoses of the Dementias[*]

	Alzheimer's Disease	Senescent Forgetfulness (Forgetfulness Phase)	Geriatric Depression	Chronic Schizophrenia	Multi-Infarct Dementia
Onset of Cognitive Impairment	Gradual process extending generally over a period of years if a proper history is obtained.	Gradual process extending over a period of several months to years.	Onset generally sudden and associated with present illness episode; however, a "life-long" history of memory problems is sometimes obtained.	An accurate history of onset is generally not obtained. However, if the patient is seen between florid episodes of the illness process, then the cognitive impairment is generally longstanding, extending for at least several years.	Sudden, "stroke-like" onset.
Course of Cognitive Impairment	Progression of the process is noted. Patient eventually becomes severely demented with incontinence, loss of ambulatory ability, etc.	No subjective or objective evidence of progression.	If associated with present episode, then the cognitive asymptomatology will remit; if associated with "chronic depression," then remains the same, patients *do not* become severely demented.	If not associated with an acute episode of the illness, then the cognitive impairment generally continues to worsen over the course of decades. Patients do not become incontinent, do not lose ambulatory ability; speech is, however, sometimes severely compromised.	"Stepwise course" with remissions and exacerbations.
Clinical Cognitive Symptomatology	As described in Tables I and II. Deficit proceeds relatively uniformly on concentration, recent memory, past memory, and functioning and orientation axes.	Subjective complaints of cognitive deficit only. No clinically objective evidence of cognitive deterioration is obtained.	Deficits are particularly notable, when present at all, in concentration and in functioning. Despite complaints of "memory problems," there may be no objective evidence of deficit whatever. Sometimes, these patients, despite excellent recent recall, can remember little with respect to their childhood; this latter deficit is most frequently related to active denial.	Deficits in concentration and functioning are notable; memory for past may be denied. Recent memory is frequently intact. Deficits have been classically described in: concentration, attention, insight, judgement, orientation, and affect.	"Emotional incontinence is frequently noted," e.g., patient may suddenly begin to cry for no apparent reason. Otherwise, clinical symptomatology is variable.
Associated Clinical Symptomatology	As discussed in text and in Tables I and II.	Very mild anxiety and/or depression are only associated symptoms; alternatively, the patient may have no associated clinical symptomatology whatever.	Associated mood disturbances with dysphoria, depression and sadness. Anxiety is frequently associated. "Vegetative symptoms" also frequently occur, these include: sleep and appetite disturbances (insomnia or hypersomnia; anorexia or hyperphagia). Anergia is another frequent symptom.	There is a history of florid psychotic symptomatology with delusions and/or hallucinations, and/or "suspiciousness," and/or paranoia.	Risk factors for cerebral vascular disease are generally present. May be history of blackouts. Peripheral vascular and cardiovascular disease is frequently present, notably including hypertension.

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[*] From B. Reisburg: "Clinical Presentation, Diagnosis, and Symptomatology of Age-Associated Cognitive Decline and Alzheimer's Disease," in *Alzheimer's Disease: The Standard Reference Book*, B. Reisberg (Ed.), Free Press (Macmillan), 1983.

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Moral and Ethical Dilemmas for the Individual, the Family and Society

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I thank you for the introduction. Lawyers tend to have a poor reputation among health care professionals; I'm grateful for the warm welcome. And hopefully, through my own work, I can further develop a counterpoint to that negative image.

First off, let me introduce myself. I am the lawyer *at* Montefiore and not *for* Montefiore Medical Center. This is a distinction which legal counsel for the hospital and I both appreciate. My job is to develop projects in law and medicine—specifically around what I call the rights of underserved populations.

Much of my work over the last eight years has involved working with the right to health care in prisons and jails. As some of you know, there is a constitutional right to care, supported by the eighth amendment. In the last few years my focus has shifted to geriatric care and most especially to the care of Alzheimer's patients.

I came to this area in somewhat the same abstract route that led me to prison health care. I first became interested in prison health care because of its connection with constitutional law. As there is a constitutional right to care in correctional institutions, based on interpretations of the 8th amendment, medicine and law meet not on a plane of malpractice—where in my experience no useful dialogue is possible, but rather around a discussion of appropriate standards of care. Alzheimer's Disease directly relates to the legal concept of personal competence, and that's what first drew my interest to the subject five years ago. The law does not know what it means by competence. Psychiatry is conflicted and medicine uncertain. But it seemed to me then, as it does now, that when we are caring for and treating patients who are at least, for this moment, on a path of inexorably declining competence, we in the fields outside of medicine need to struggle with medicine to improve, hone and make more sophisticated our understanding of what these concepts are and what the concomitant rights of patients are. These are the concerns of a lawyer who is part of an interdisciplinary health care team at a medical center. How are those concerns different from the concerns of my able colleagues who spoke before? My primary concerns are with concepts of rights, and additionally with concepts of fairness and justice.

Specifically for the purposes of this discussion, for patients of diminishing capacity, how can these concepts be defined and secured? The tools of a lawyer are peculiar and particular. They are not the tools of a legislature or a judge. But they do include a focus on process and procedure. The goal of a lawyer, as I see it in this context, is to try to bring some new sort of clarity to the complex world that involves the allocation of decision-making authority among family, patient and providers.

You may properly query, what is my bias in all this interaction? My bias is that without the open engagement of issues and without the difficult grappling with conflicting and competing agendas and perspectives—which are always present in health care—the voice of the least powerful will fail to be heard above the din. And in our case the least powerful tend to be the patients afflicted with Alzheimer's Disease. If the perception of the law can add anything to the sensitive experience of the caregivers and the scientists who have spoken before me and will address you this afternoon, it is perhaps by the gentle but firm insistence that abstract rights are empty protections without clear procedures to guide and to govern their implementation.

Question: What are these rights? What do I mean by the rights of patients in the context of this devastating disease? And let me point out that I do not mean to infer by discussing the rights of patients that there are not concomitant sets of rights, possessed by families and caregivers. However, in the very few minutes provided to me I must relegate those issues to a different time.

Therefore, I would suggest to you that there are three basic rights. First is the *right to know*. That is a right clearly possessed by all patients. Obviously for a patient with Alzheimer's Disease, it is a particularly complex right. It is particularly difficult for caregivers to respond to. But there is a right to know. I would argue, furthermore, that there is a right to know as early as possible, because that is when the capabilities are most intact. There is a right to know about diagnosis and prognosis and to be provided, within that context, with the assurance of care and comfort if not cure. I realize that some consider this merely a radical position, and some consider it ludicrous. However, it is my experience and the experience of those lawyers with whom I work that most Alzheimer's patients know, experience, and sense their illness and their decline.

There is often a conspiracy of silence between and among families and providers. I do not think it serves the interests of patients, families or providers. What it does to the patient is ensure that the early confrontation with that disease proceeds more alone and with more solitary fear and trembling than may be necessary.

The right to know is of course a preliminary to that second right which is a *right to decide*. How long to live or die as a demented patient can be at issue. There are decisions to be made about the disposition of real property and personal property, about assets and long-term estate planning. There are good-byes to be said and relationships to be addressed—all issues which can only be confronted and approached once there has been some information shared.

The law takes rights seriously and rights in the abstract must be provided with protections and process to be assured.

I, therefore, come to a third right. First *the right to know*, second *the right to decide* and third *the right to be provided with a framework for decision-making*. This is a right which joins the patient, the family and the provider. Decisions by a person when competent, even if somewhat compromised or disabled and even if unwise, are the best expression of individual will and therefore, in our society, the most deserving of our respect. The problem with a patient afflicted with Alzheimer's, as we all know, is that we're no longer dealing with a clear, concise, comprehensive and strong statement of will. However, we may be dealing with what I've come to call *residual will*. How do we ferret out this residual of autonomy? We know only by asking early on the key questions to determine personal preference.

The law has yet to adequately consider the peculiar, terrible and awesome sorts of decisions which must be faced by patients and families. There are, with very few exceptions, very few legal opinions that deal with rights in this area. There is almost no legislation. That I think is a task that we can all struggle together to change. From my perspective there are three very clear changes in the legal framework which should arise from the greater focus on and by Alzheimer's patients and families. Number one, we need to define and give power to the sense of abilities, perceptions, and residual will which are attested to by families and exhibited by patients.

We need to know what specific abilities entitle a patient to operate in which sphere. What *is* their level of competency? When can a patient execute a living will or sign a power of attorney, even if afflicted with Alzheimer's Disease? Secondly, I think we need to develop patterns of practice which are designed to prevent rather than withhold information. Third, we must present research and data to legislators to ask them to help fashion new schemes and statutes to address the particular problems of patients with declining, diminished, or extinguished capacity. We need to develop, for example, durable powers of attorney, that clearly permit third parties to manage property and to control health care decisions. And perhaps we need to develop legislation which permits patients to consent, in advance, to later research protocol which will help us to learn more. Finally, I think we need to be courageous. In the face of an illness which is devastating to patients, families and caregivers, we need to permit decisions about care to "come out of the closet"—to be the possible role of the law.

Medical Concerns

by Saul V. Moroff, M.D.
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Panelist

Physicians don't yet, for the most part, treat patients for Alzheimer's Disease, but they do treat many Alzheimer's patients for other concurrent diseases. In the course of such treatment, a number of ethical issues emerge; some are unrecognized or ignored by physicians, but more are being confronted, particularly in settings such as hospitals, where the concentration of doctors and other professionals yields a critical mass for debate.

Let me raise four questions which doctors face in treating Alzheimer's Disease patients. First, who should make treatment decisions; whose consent should the doctor seek? I think it's important to recognize that competence—in the sense of a person's understanding of what is proposed and being able to grant or withhold informed consent—is not a simple yes-or-no state, but one which permits many gradations. A diagnosis of Alzheimer's Disease does not in itself make a patient incompetent to agree to or reject medical treatment. Certainly, treatments which are straightforward, carry minimal risk and offer obvious benefits should be discussed with the patient to the extent that he is capable of understanding, even when some degree of memory loss and impaired judgement are present. In more advanced states where comprehension is difficult or impossible, simple courtesy and respect for personhood should lead the physician to inform the patient of ongoing events and ask his permission to treat. If the patient should then refuse, even if others have already consented on his behalf, the doctor should, at the least, think again about the strength of the necessity to treat.

If and when the patient can't give informed consent, who should decide? Most of us would agree that the patient's spouse should do so, with the doctor functioning as advisor, as technical expert, as prognosticator, even as a friend, but not as an independent, paternalistic decision-maker. If there is no spouse, then adult children should be consulted, and if they're not available, then others who have been close to the patient through ties of family or friendship. Rather than following any fixed sequence of responsibility, however, it would be even better if the patient were able, when he or she was still competent, to name a relative or friend as having a durable power of attorney, authorized to make ongoing treatment decisions as the need arises. There is some danger in having treatment decisions made by close relatives; they may insist on overly vigorous therapy out of their own sense of guilt or grief, or they may refuse treatment inappropriately because of their anger and their exhaustion.

This leads us to the second question: to what degree should doctors and relatives consider the quality of the patient's life in making treatment decisions, particularly as those decisions involve potential prolongation of life? It is natural for a healthy person to view the prospect of becoming demented with horror, and to believe therefore that such a life is not worth living. Persons actually in that state, on the other hand, especially if they have no memory of their disease-free past, may experience substantially less distress than do their doctors and relatives. When we invoke quality-of-life issues, we may be projecting an unhappiness that is more ours than the patient's. Even a patient who, early in the course of the disease, gives treatment instructions based on his anticipation of an unacceptable quality of life, really has no way of knowing how he will feel when his disease becomes more advanced. It is more important, I think, to try to determine how much distress and unhappiness the patient is suffering than to consider whether we or the patient would choose voluntarily to face the prospect of such a life.

The third question we must ask is what is the purpose of treatment in each medical encounter? One aim might be to treat the Alzheimer's Disease itself, a goal so far with little success. More likely, we will find that the doctor is aiming to relieve pain or other suffering; to improve or preserve function; or to prolong life. I view the sequence of these three goals as increasingly problematic for the patient with Alzheimer's. Surely all persons are entitled to relief from suffering, and to withhold such treatment would be ethically and humanely unacceptable. Treatment aimed at dysfunction—the improvement, for example, of defective hearing or vision—may be reasonable and even desirable, particularly when cognitive functions are impaired and the ability to cope with physical dysfunction is diminished. On the other hand, I am more than a little troubled by the concept of treatment aimed solely at the prolongation of life, such as therapy for asymptomatic cancer or treatment of serious infection in a patient no longer aware of his environment. I personally find such treatment difficult to justify.

Rather than employ the recent practice of classifying medical treatment as "ordinary" or "extraordinary" on the basis of cost or technical complexity, I prefer to do so on the basis of the intent of the treatment. I would, for example, regard major surgery to relieve intolerable pain from intestinal obstruction as ordinary, and the use of blood transfusion for hemorrhage in an irreversibly comatose patient as extraordinary.

The decision to treat, I think, must also be tempered by the patient's limited ability to understand and to cooperate. There are painful or distressing treatments which we might accept for ourselves because we are convinced of the worth of the benefits we hope to derive from them. The same treatment to a confused and frightened patient deserves careful deliberation if it can be delivered only by tying him down.

Finally, let me mention those questions which physicians are often reluctant to ask, and even more reluctant to answer, namely those which involve costs and the use of limited resources. At the "micro" level, doctors do make such decisions daily when, for example, they decide whether an acutely ill patient with Alzheimer's Disease should be admitted to or excluded from the last bed in the Intensive Care Unit. Limited resource decisions are made less dramatically when busy hospital residents and nurses allocate the time they devote to each of their patients. Though doctors may believe that they do not discriminate among the patients who compete for beds and for their attention, they do so constantly, and there is no question but that they are influenced by the patients' mental state.

At the "macro" level, doctors have traditionally avoided allowing considerations of societal priorities to enter into decisions concerning individual patients; yet as physicians and other professional health workers, we really must start thinking about costs and benefits. What are the nationwide medical costs for the care of Alzheimer's patients in their last year of life? How much support can or should our society give to such patients and their families? Should limits be placed on this support? We face the difficult dilemma of balancing the need for humane treatment and revulsion against the specter of active or passive euthanasia with the near impossibility of developing sufficient resources to satisfy all the needs of our sickest patients. There is an irony in American medicine today: we are spending more and more money and time on those patients least likely to benefit from them. Individual doctors and the families of those patients need guidance from both ethicists and economists in deciding when, if ever, enough is enough.

The Family's Viewpoint

by Marion Roach
The New York Times
Panelist

My name is Marion Roach. I wrote an article which appeared in the New York Times magazine in January of this year on the subject of my family's experience with Alzheimer's Disease. I am one of two daughters of a victim.

Late in 1979 I began to think that my mother was going mad. I called it madness—to myself—at first, because I thought her behavior impossible to understand or explain.

My mother was an independent and wilfull person. In her life she has been a precious only child, a good student, a beautiful sorority sister, a newspaper reporter, a wife, a mother, a girl scout leader, a visiting nurse volunteer and a teacher at a bilingual school on the lower east side of Manhattan.

In the progression of her disease she has been forgetful, then frightened, depressed, angry, paranoid, hostile and incompetent. She is now completely dependent upon the aid of others. She cannot be left alone. She is repetitive and confused. She is agitated. She cannot read. She cannot drive. She cannot always form complete sentences. She frequently speaks rapid gibberish. She cannot bathe properly. She has no short term memory. With the progression of the disease, she will almost assuredly lose control over all of her bodily functions; she will have to be fed, cleaned and dressed.

My mother is 54 years old. She is suffering from senility. She is suffering from the humiliation of having her dignity wrenched from her. She is losing her mind in handfuls.

She is one of two million known people in America who are suffering from the fourth leading killer in this country, and in New York City, where we live, in this age of modern medicine and progressive government, my sister and I can barely get a decent day's aid, an intelligent suggestion which is within our economic means or an understanding nod from anyone who has not known this disease firsthand.

Alzheimer's Disease is a brain disorder which causes a progressive and relentless loss of intellectual and physical functioning. At this time there is no cure for Alzheimer's Disease. Treatment is limited and experimental. We do not know if it is viral or genetic. We do not know if they catch it, or if they pass it along.

We have before us an issue which affects every resident of this country. There is no one who does not or has not known a victim or someone who cares for a victim.

When my mother was first diagnosed as an Alzheimer's victim, the doctor said, "your mother is not going to die." We thought these words were being offered in comfort, as reassurance. Our father died five years ago of cancer of the bone marrow. We did not want our mother to suffer too. We have since learned that the doctor's words were preparing us for extended suffering, with no quick end, no definite release for her—and for us—in sight.

I have come to think of Alzheimer's Disease as a monster which is trying—plotting daily—to take more than one victim. It doesn't seem satisfied with the horror it has made of my mother's stately composure, of her years of education, of her emotional balance and insight. The disease is, as I envision it, trying to take my sister and me too. But we won't have it.

I have been asked to speak about Ethics and Moral Dilemmas. A year ago I would have argued that I could better speak about the Science of Panic, or How Panic Breeds Ingenuity.

Now, I realize, however, that this subject of Ethics and Moral Dilemmas is appropriate. I realize that my ethics have changed because my morals seemed undereducated and not up to the task.

An Alzheimer's patient is likely to say and do anything before he or she can do virtually nothing for themselves.

And so, the dilemma begins with the illness.

As a family member, one wonders about compensating for the illness; from answering questions for the victim to limiting their freedom of movement.

In the very beginning I believed that my mother—because she was the mother—had the right to an independent life. My experiences, however, were eroding that belief. The dilemma was resolved when I realized that restricting her movement protected her and protected others. We took away her car keys and stopped her from going out unattended.

But can you tell me how to live with decision—how to resolve the personal dilemma of locking her telephones? She was harassing the neighbors, dialing the operator literally twenty times an hour to ask what day it was, what time. The dilemma took its toll every time she'd stare at the locked phone and then look at me and ask why we had done that.

Last week my sister phoned me and asked "When is the book coming?" I am writing a book on Alzheimer's Disease. I was annoyed at the question. I get it from my publisher. "When I finish it," I replied. This is not how I answer my publisher. "No, no," said Margaret, "the one which comes in the mail and tells us what to do next, how to cope."

We try to make light of anything we can. We try to keep a strong sense of humor. I would be interested to know how much is enough, too much.

After the diagnosis, my sister and I wrestled with the decision of whether or not to tell my mother what she has. Some of her closest friends suggested that we do. Others encouraged us not to. My mother had always told me when I was a child that she "never wanted to be a burden" when she got older.

Someone suggested—a close friend—that we tell her what she has so she could kill herself; that if she knew what she had she wouldn't want to live.

We told my mother what she has. She doesn't remember. She says she had a stroke. She says, some days, that her memory is bad. She senses her decline but she cannot contribute to her own care. When we told her, she was already too far into the disease to comprehend its meanings. Should we have known sooner? Should we have told her immediately? I would be interested to know.

Following the diagnosis, we looked everywhere for information. There was no listing in the local phone book. There was no entry in the encyclopedia. The dictionary listed senile as "pertaining to, characteristic of, or proceeding from old age." The entry for senility reads, "the state of being senile, mental and physical deterioration with old age."

My mother is not old.

At the time of the diagnosis, and until only two months ago, she had a cross court backhand in tennis that was frightening. She still swims laps, and would swim more often, if many of the people at her local pool hadn't made her feel terribly uncomfortable by shunning her, because of her disease. I would like to know how many of them deserve my understanding.

Just eight years after completing her Masters degree in education, she had to take a leave and then finally quit her teaching job. Her disability status could not be guaranteed because we were told initially that this disease was not considered a disability, and that therefore we could not be assured disability payments which would be the only way, two years later, to qualify for Medicare.

In the meantime we were advised to transfer her funds to provide for her care, transfer any ownership she had, and take power of attorney so that she should appear destitute. I would like to know if I am lying and, if so, if it's alright. It did not make sense in the beginning, but with virtually no home care or nursing home benefits available from the federal government, we were facing costs of approximately $30,000 a year, unreimbursable, for her care.

The federal insurance system is geared to underwrite treatable diseases. There is no treatment for Alzheimer's Disease, only what professionals call management or custodial care. The patients have to be watched and that is not considered an expense for which the family should be reimbursed. Medicare is for the old, Medicaid for the poor. We, the middle income family, are left to fend for ourselves. I would like to know if this is just.

Economics should not be the most important factor in a family's decision as to whether or not to institutionalize a loved one. I know that.

As my mother's illness progresses, the type of care she requires becomes more complicated. At first a responsible person with only babysitting skills was necessary. Now, she needs careful policing—to keep her from leaving on the gas burners, to get her to flush the toilet and to bathe. Soon, she will need total care. She will lose all her privacy and we, as daughters, will put her completely in the hands of strangers. I would like to know if this is alright. I need to believe it is.

Perhaps this is hard to comprehend. Perhaps it is difficult to understand why anyone would give up the care of a loved one to a hired person. My sister and I work. It is impossible to spend all day taking care of my mother and still work to support her. But that is not the sole reason for the help. Caring for an Alzheimer's victim is a relentless and sometimes thankless task. They are unable to remember the slightest recent detail, and therefore unable to understand the care being given; eventually unable to recognize the person administering the care. They present constant questions when they are still able to speak and need constant attention to keep them from getting into trouble.

Medicating an Alzheimer's patient presents its own dilemma. It is hard to accept the fact that I am sedating my mother. It took a long time for me to understand that by managing her properly we are preserving her shreds of awareness; that without all her agitation, she is better able to cope with life, and we with her. At first, though, I was guilty of not knowing how much was enough, too much. I sometimes still need to know that medicating her is alright.

Perhaps you are getting my point. Perhaps you just think there is a lot I'd like to know.

There is, for every person touched by this disease, a great deal to learn, a great deal to try and a great deal to accept. Our dilemmas must breed commitment. Otherwise, they are only painful. We must be committed to change; to change the attitude toward diseases of the mind, the attitude toward the elderly.

We must work equally toward acceptance of a description and diagnosis made in life as well as acceptance and understanding of the pathological research so that we can combat this illness with the necessary funding and legislative change. We must have a cohesive network of care.

My mother is daily, falling freely into her gradual demise. It is a terrible thing to watch. Had she been in her eighties, my sister and I might have been guilty of the same thing which has existed through history—of assuming that senility is a natural partner of aging. We might then have learned to live with it without seeking alternative care. My mother is supposed to be in the prime of her life. She is suffering from a disease which is the leading cause of senility regardless of the age of onset. There is nothing natural about it. There is nothing acceptable about it. My dilemmas are reduced to this: Alzheimer's Disease is a horror, and it is here with us, and will be until we attack it in earnest.

Thank you.

Ethical Issues

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Panelist

The individual with cognitive loss calls into stark relief basic value conflicts and ethical dilemmas. These dilemmas involve the very core of our value foundation and raise questions regarding the meaning and value of life, the rights and responsibilities of families, the distribution of scarce resources, and the tension between the autonomy of the individual and the common good. Dementing illness of any type is a human tragedy, but the insidious nature of Alzheimer's Disease and related disorders raises particularly thorny problems for the patient, the family and care providers.

The Individual

The autonomy of the individual is a basic human value. Bodily integrity, religious freedom, and individual self-determination have each been used to support the concept of personal autonomy, which refers to the individual's right to make decisions which are voluntary and intentional and not the result of coercion, duress or undue influence. Stated quite simply by John Stuart Mill in 1895:

> "Neither one person, nor any number of persons, is warranted in saying to another human creature of ripe years, that he shall not do with his life for his own benefit what he chooses to do with it."

In a technical sense, few, if any, individual decisions are truly autonomous. The individual is constrained by the available choices and his own strengths and weaknesses, and is influenced by the wishes of others. For the person with dementia, however, the issue of autonomy is even more complex. Although the ability to make decisions is, by definition, compromised, Alzheimer's patients as a group vary widely in cognitive ability, and individual function may vary from moment to moment. In many instances, however, *all* decision-making is taken away, with no recognition that for the Alzheimer's patient, competence falls along a continuum rather than forming a dichotomy. The rationale for such an assault on autonomy is usually based on one of two other values: paternalism and the common good.

Paternalism is the "interference with a person's liberty of action, justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced" (Dworkin, 1972). Paternalism is frequently practiced with the best of intentions, particularly under circumstances in which the individual for whom decisions are being made is unable to make decisions for himself (Dworkin, 1971). Unfortunately, society often takes a paternalistic approach with older persons even when there is no evidence indicating that decision-making capability is compromised. Paternalistic behaviors may include a physician providing only partial information to a patient regarding test results, or reporting diagnoses and prognosis to a family member rather than the elder himself, or a family making the decision to place an elder in a nursing home without consulting him regarding his thoughts on the matter.

Non-inclusion of the elder in the decision process carries with it the potential to harm despite our best intentions. One risk is that bad decisions will be made because of incomplete information. Missing information may relate to the wishes of the patient, his fears, expectations, financial situation, circumstances at home or even symptoms of disease. Another potential harm is "learned helplessness." Simply stated, if we treat an individual as if he is helpless, he is likely to become helpless. Research (Avorn, 1982) has demonstrated that if we place an individual in a more restrictive setting than is needed or provide unnecessary supports, the individual's behavior may indeed change to meet the expectations of the environment, with loss of function and life quality in the exchange.

However, there is a growing recognition of the limits of autonomy. Does an individual have the right to choose a course of action which compromises the common good? Circumstances in which the common good supercedes personal autonomy include the quarantine of patients with highly contagious diseases or the confinement of individuals who are considered to be a threat to others. This common good argument is also used to justify the placement of frail elders into nursing homes. The reasoning runs like this. Because resources are so scarce, when it becomes more expensive to maintain the individual at home than in a care facility, he or she should be transferred to the nursing home. In these times of budget austerity, it might well be asked if an elder patient has the right to refuse treatment when such a refusal is likely to result in large and avoidable expenditure of public monies in the long run, or demand care at home when placement in a nursing home is more "cost-effective." The balancing of personal autonomy with other values is particularly difficult when public monies are involved.

The Family

Care of the individual with Alzheimer's Disease raises difficult issues for family members as well. Shifts in dependency relationships are likely to occur as an older person becomes progressively functionally impaired. These shifts change patterns of interaction within the family and call into question long-accustomed styles of decision-making and power relationships. A confusion of values affects the determination of the appropriate level of support to expect from a family for their older members. Contrary to popular opinion, families are not rushing to dump their impaired elder members into nursing homes. It has been estimated that as much as 80% of home care is provided by family members (Brody, 1978; Comptroller General, 1979) and, although not reimbursed by Medicaid, this care is not without costs. Studies of informal home care of Alzheimer's patients show that family providers are likely to be suffering a variety of stress-related problems including alcohol and drug abuse, depression, divorce and physical diseases thought to have strong psychosomatic components. Care is often provided by spouses and children until the physical and emotional resources of the family have been all but depleted.

And yet, efforts are under way to increase the level of responsibility of families for the care of their elder members. States now may choose to seek support from families to supplement Medicaid for elders in nursing homes. The political and practical problems in implementing this policy are enormous, but the issue is directly related to the broader question of intergenerational responsibilities (Daniels, 1982). What does one generation owe another, or more generally, how do we distribute scarce resources among generations? A full examination of this issue is certainly beyond the scope of this discussion, but this unanswered question shadows the formulation of health policy for this country.

The Health Care System

Value considerations determine distribution of resources within the health care system, influence the enactment of laws and enforcement of regulations, and provide the framework for policymaking. The current distribution of health resources is biased in a variety of ways. First, public monies are more likely to be spent for medical/technical services vs. social services; more likely to pay for institutional services in hospitals and nursing homes vs. services which keep elders in their own homes; and are more likely to pay for later, more intrusive interventions vs. earlier interventions which support the elder, his family, and other informal care providers (Fox, 1981).

Public monies for nursing home care are only available to those who have exhausted virtually all of their personal resources (via Medicaid "spend-down"), or who have had the foresight and professional assistance to divest themselves of such resources. Despite state efforts to apply the ethic of equity, public reimbursement for nursing home care for two individuals with identical needs living in the same state may vary by as much as $70 per day.

The egalitarian view would suggest a distribution of resources in which each person receives equal opportunity of access to care. Certain of the voucher proposals currently under discussion in the Department of Health and Human Services use this as their basic rationale. Others would argue that allocation of resources should be based upon need. But once again we run into difficulties defining need, as well as approaching the technological possibility of almost limitless need for some individuals. The capacity to keep patients alive indefinitely through the application of extremely expensive technology continues to develop. Under a view of distributive justice, resources might be allocated differentially throughout the life span based upon assumptions concerning which interventions are most appropriate at various ages.

Apart from the allocation of resources, a number of value issues arise in the delivery of care for patients with Alzheimer's Disease, particularly when they become severely disabled and are no longer able to participate in decision-making. For these individuals, surrogates may provide information regarding previously stated preferences, previous behaviors and lifestyle choices. In the absence of stated preferences, therapeutic activism is indicated, including thorough assessment and treatment. Providing appropriate treatment for illness will not only improve the quality of life for the individual, but is imperative in maintaining the highest possible level of function. However, there are circumstances in which forgoing treatment may be the most compassionate and appropriate intervention. There are patients whose quality of life is so compromised that it is no longer worth living.

This is a difficult and tragic issue. There are those who believe that in the absence of stated preference, we must always assume a desire to live. Sanctity of life is a central ethic in the Judeo/Christian value system. It is argued that we should avoid the "slippery slope" of determining for others that some lives are *not* worth living. I would argue that the footing is no more secure on the side which states that life must be maintained no matter what the costs. Most of us fear maintenance in a dependent, vegetative or actively suffering state more than we fear death itself.

But decisions to withhold treatment and resuscitation must be made with the utmost of care. Decisions which result in non-treatment of impaired elders are made daily in hospitals and nursing homes across the country. Some are based in compassion, caring and full consideration of the ethical issues and value conflicts involved... others are made as a matter of expedience with little consideration and less discussion.

Compassionate care-taking requires that decisions such as these be made in the bright light of open consideration of the many relevant values and points of view, and involve family members, care-providers, clergy and if possible the elder himself, directly (early in his illness) or through surrogates. Decisions must be made on a case by case basis with clearly stated policy regarding the process of the decision... taking care to avoid blanket decisions involving classes of patients.

Care of the Alzheimer's patient will always involve difficult decisions and tragic choices. Clarification of assumptions, values and beliefs of each of the participants is an important part of the decision-making process. Decisions will not be easy nor will value conflicts be easily resolved. But if values and ethics are more openly considered, the process of decision-making will be facilitated and the outcomes of that process will be more satisfying. And in the final assessment, we will achieve not only a better quality of life for those that we care for but also a better quality of life for those who provide that care.

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The Eli Goldstein Memorial Humanitarian Award Luncheon honoring Sen. Mark O. Hatfield

Opening Remarks

by Mr. Irving H. Stolz
President
The Hebrew Home for the Aged in Riverdale

For those of you who are familiar with the Hebrew Home for the Aged in Riverdale , I welcome you once again with my heartiest good wishes. And for those of you who are passing through our doors for the first time, allow me to greet you in a spirit of friendship and brotherhood. I can think of no prouder occasion on which to extend my feelings than here, at The Martin Steinberg Memorial Symposium on Alzheimer's Disease and Related Disorders. The presence of each and every one of you is a direct tribute to Dr. Eli Goldstein, to whom our Humanitarian Award is dedicated this year. A special welcome goes to my good friend, Mr. Milton Gilbert, who has coordinated and propelled this event from a germ of an idea to full fruition. And to Senator Mark Hatfield of Oregon: your participation and your interest in this symposium have been integral. It is vital that our lawmakers and representatives take an interest in the physical well-being of *all* citizens, including the elderly, infirm and disabled. It is easy to doff a cap to fit the mood of the day, but to champion a cause less known, to fight for the rights of those less able—that takes courage, a characteristic of the conscientious and treasured official.

The cause today, of course, is the study, treatment and cure of Alzheimer's Disease, its effects, its victims. If I describe Alzheimer's as an "obscure" disease, I am not belittling its significance, consequences, or its devastation. Instead, I am lamenting the fact that Alzheimer's Disease research has proceeded so slowly, that progress has proved so difficult, that so many facts have remained unclear, and that so few people have contemplated its seriousness or its nearness to us all.

First described in 1906 by Alois Alzheimer, it has remained somewhat of a mystery to the health professionals and researchers who have studied it since. In fact, only in the last 10 years have major insights been gleaned in the isolation, description and treatment of Alzheimer's. We know now that there are many types of senility. Alzheimer's Disease has been described as "the most relentless and devastating" of all these forms.

At the Hebrew Home for the Aged, we are directly concerned with Alzheimer's Disease and its effect on those of our residents who suffer from it. Alzheimer's can strike at any age, but it strikes the elderly most often.

Many of our residents are afflicted with Alzheimer's. It is for those residents—and because we regard Alzheimer's as an ultimate threat to our society—that we have opted for a position in the vanguard of research on Alzheimer's Disease. In late 1983 we received New York State authorization to begin the reconstruction of a satellite facility, which will be the first institution in the nation exclusively devoted to research and treatment of Alzheimer's Disease.

This symposium illustrates our commitment to bringing Alzheimer's Disease out into the open for public discussion and understanding. Like "cancer," Alzheimer's is a disease that has a broad and indiscriminate outreach. Everyone is a potential victim at some time in his life. The Hebrew Home for the Aged will not remain silent on the real and present danger of Alzheimer's.

We believe that the Home is not a storage space for the elderly, like so many sticks of furniture too good to throw out and not good enough to use and display. We don't want to see all of our elderly in nursing homes. We want those who can to pursue independently active and profitable lives and are committed to improving patient health to the end. For those who need us, we want to be more than a nursing home, but rather a nurturing home-away-from-home for those unable to care for themselves. This is a philosophy we have pursued for 67 years and will continue to pursue.

Dr. Eli Goldstein, for years the chairman of the Medical Board, inculcated in all of us his belief that the Hebrew Home for the Aged should provide a "total response"—including the best medicine, the best research, the best psychiatric care and social services with tender loving care.

Dr. Goldstein was a man who loved his patients and who loved his work and he never stopped exploring the tenets of that work. We salute him today, knowing that he would have leapt head first into this symposium: speaking, trading ideas and learning with the unquenchable thirst for knowledge that made him an unrivalled physician and a model of a man. His memory lives on in his widow, Mrs. Eli Goldstein, who is here with us today. She should indeed be proud to have shared and to have loved such a charismatic and dedicated individual.

Martin Steinberg was not a physician, yet his concern for the health and welfare of those around him—and society at large—was boundless. He was a philanthropist, and a friend of the Home. His wife, Mrs. Martin Steinberg, is here with us today. She deserves extra special thanks. By providing the essential funding for the Symposium, she has insured that Martin Steinberg will continue to play a leadership role in our present and our future. And now, allow me to introduce Mr. Milton Gilbert, who is the Chairman of the Board of the Hebrew Home. Mr. Gilbert.

Award Presentation

by Milton A. Gilbert
Chairman, Board of Directors
The Hebrew Home for the Aged in Riverdale

Good afternoon. Thank you, Irving, for your very cogent remarks on the little-understood seriousness of Alzheimer's Disease, and the Home's commitment to finding the causes and the cure. Alzheimer's is a ticking bomb timed to go off before we have turned our back on this century. By the year 2000 one out of four Americans will be 65 or older. We cannot afford to have a full quarter of our population vulnerable to a chronic, incurable, although not necessarily terminal, illness. As medicine has offered us new technology and procedures to prolong life, we as gerontologists, as Americans, as human beings, insist on quality of life. Nothing less than a longer, active, profitable, healthy life will do. To prolong life without health is an irresponsible act. We must not go into the 21st century without a responsible commitment to our aging and our future.

You here today have made this commitment or you would not be here. Let me extend my thanks to all of you and reassure you that the Martin Steinberg Inaugural Memorial Symposium is the first of many events to be sponsored by the Home, sharing new research and treatment methodologies and bringing our insistent message to the hundreds of doctors, nurses, researchers, administrators, teachers and others who work in the area of geriatrics.

We are joined today by our very distinguished senator from Oregon, Sen. Mark Hatfield, the Inaugural Recipient of the Eli Goldstein Humanitarian Award. Old age is not a particularly rewarding subject area for a politician, but Senator Hatfield has made aging his issue. In fact, Senator Hatfield has regularly tackled issues that are unpopular. I do not think there is a politician in Washington with his candor, sensitivity or courage. He does not give mere lip service to an issue. He lives the issue, he fights for what he believes and he puts his words into action.

Washington has never been known for its interest in the affairs of the elderly. And Alzheimer's Disease is hardly a sensational headline-grabbing issue. Yet, for the 500,000 Americans suffering from senile dementia of the Alzheimer's type, their families and friends, this is an urgent and vital issue. We are not talking about guerrilla coups in Central America, starvation in West Africa or murder in Asia, we are talking about a needless waste of life among our own people and in our own homes.

It is so easy for gerontological issues to be neglected, to fall out of sight among more immediate priorities. Certainly, there are special interest groups in Washington dedicated to representing the concerns of the aged. But their power is empty without a strong political hand guiding them and opening the doors to policymakers and those who appropriate money for research, who have a grip on our lifeline.

Mark Hatfield has that grip and has used it along with Sen. Thomas Eagleton of Missouri. He has sponsored the Hatfield-Eagleton Bill, which would provide more federal funding for the research and treatment of Alzheimer's Disease. This may not be grandstand politics, but it is sound economy and an investment in our future. Alzheimer's Disease victims account for a disproportionate share of this country's long-term health care, a sum that approaches 30 billion dollars. Above all, the Hatfield-Eagleton bill speaks directly to those who have known the terror of the disease, those who have seen it affect their friends and their loved ones, their parents, siblings and spouses.

Allow me now, Senator Hatfield, to congratulate you and to thank you for your efforts. We are pleased and honored to award you the first Eli Goldstein Humanitarian Award. You have brought respect, sincerity and a remarkable degree of energy and commitment to the office of senator. Your contributions to the study and understanding of Alzheimer's Disease have earned the applause of everyone here. Thank you.

Acceptance Remarks

by Senator Mark O. Hatfield

Thank you very much, Mr. Gilbert. It's indeed a great pleasure for me to be here today. I've been to many homes for the aged over my 33 years in public office, and I am greatly surprised and astonished by the innovation, by the marvelous sense of caring and compassion that is so evident here in Riverdale. By using the words "surprised" and "astonished" I'm reminded of a story about Noah Webster, the great 19th century lexicographer. Seems one time Mr. Webster was in the kitchen making amorous advances towards the maid when *Mrs.* Webster decided to enter the room. She exclaimed, "Mr. Webster, I am surprised!" And in his precise knowledge of the English language, he retorted, "No, Mrs. Webster. *You* are astonished; *I* am surprised." Of course the Hebrew Home is not the Webster's kitchen, but once again, let me register my delight to be among you today.

I'm going to do something that is perhaps a little unique in a politician's career—submit my remarks for the record. For a few moments I'd like to summarize my thoughts and share them with you today.

These are difficult times. I'm not only speaking of the international scene and the political crises we face from one end of the world to the other. I also speak of our own domestic picture, the economic recession and our struggle to recover from that recession. I speak of the growing sense of disconnectedness among our people, and the adversarial relationships that have arisen among us.

One of the most difficult things I face as a politician is to sit as chairman of the Appropriations Committee and see over eight hundred billion dollars of your tax money being allocated for various and sundry programs. What I sense is a great imbalance. I know that many of you are aware of the fact that your government has committed itself to spending one trillion seven hundred billion dollars in the next five years for war armaments. I don't think you have to be a hawk or a dove, a pacifist or a war monger; I am talking about simple, humanitarian instincts. A cursory view of the nation of which we are a part and its needs would lead one to say: something is out of balance when we have to scrounge to find twenty-two million dollars for research on Alzheimer's Disease and we raised that from the magnificent sum of 3.8 million dollars a few years ago. We can commit ourselves to a hundred million dollars down payment on the resurrection of a chemical weapon that is totally unnecessary for our arsenal, and a hundred million dollar down payment on a four to six billion dollar weapon system, but we can only find twenty-two million dollars for this important research on a disease that is exacting its toll in human suffering, in the wrenching experience that affects both the victims and their families.

In Los Angeles not long ago I had the great pleasure of meeting opera singer Dorothy Kurstin. She told me that her call in life is no longer singing, but to raise citizen awareness of this dreaded disease, Alzheimer's. She has been personally affected by the disease; her doctor husband diagnosed himself as a victim five years ago. For two years he kept a journal, but for the last three, he has been unable to function at all.

I suppose like many things in life, tragedies can just roll off your back if they don't affect you directly. We hear about so many programs; it is difficult to become involved in each and every one.

I, too, have had personal experience with diseases of the aging. My father, in the prime of his life, was a blacksmith, working for the Southern Pacific Railroad. You never saw a more beautifully built physique in your life. And he was a vital man. Though he didn't have an opportunity for higher education, he managed to memorize Shakespeare and to recite poetry, to maintain a love for literature. He was a renaissance man, vital, dynamic, a wonderful person.

And yet the last three years of his life, he was not my father. Physically, of course, he was, but still, I felt that ambivalence of emotion. He didn't know me, he didn't realize what was happening in the world around him, in the life of the nursing home where he resided. In many ways, I had already said my good-byes. But every time I returned to Oregon, I was drawn to that nursing home. I felt the duty, and I had an ever-flickering hope that maybe for one second, or for ten seconds, on this visit there might be some kind of return. There never was.

I confess to you that that is why I have felt that our government, our society, should be spending more of its resources to enhance human life, to sustain, to build the quality of life—instead of being so thoroughly committed to developing a higher degree of efficiency in methods and ways to destroy life. It just doesn't make sense. I hate labels, doves and hawks and all that; I'm talking about survival of humanity. I walked through the streets of Hiroshima one month after the bomb had been dropped; the bodies had not been recovered, there was a stench as well as the sight of indiscriminate devastation. And that made an indelible imprint upon my mind that I can never escape. But it also demonstrated to me in a vivid way that here, only one primitive bomb could make that kind of destruction. What would the world be if the United States of America had directed its attention to and unlocked the key to Alzheimer's, or cancer. We say our prestige, our influence in the world, will be enhanced by developing a califorce weapon known as the MX missile, the midget man missile. This at a time when two of our twenty-one nuclear submarines could destroy every major Russian city and the Navy wants to build twenty-five more. What degree of overkill do we have to have to be secure?

We are paying a very high price for this pursuit of false security. The Shah of Iran thought his arsenal was his security and he neglected his political, social and economic problems. And they overwhelmed him. And I say to you today that America's vulnerability on the security front is not in the lack of an arsenal, an adequate diversified arsenal; it is in the neglect of our infrastructure made up of health, housing, transportation, utilities, a productive economy and our over-dependence on middle eastern oil. All of these things are our true vulnerability. And the bigger bombs that we build in no way compensate for the failure to address those problems.

If you are not moved by humanitarian concerns, let me point out that the most cost-effective dollar that we can invest of your tax money is in health. It returns thirteen dollars for every dollar we invest at the federal level. There is no other program that can return to the general economy a higher yield on the investment. So if we are money grubbers and are impressed only by economics, we should think of that. And the *lowest* multiplier in creating new jobs and new wealth in our society is a dollar for arms. That's the choice.

People like you and symposiums like this will make a difference. If you think there is no time and you give up hope then let me just say a few months ago I got thirty thousand letters in two days from just the people of Oregon telling me to repeal the ten percent tax on withholding and on savings.

There is hope. You can determine the course of your government, the balance and the imbalances. And I urge you to not only be content with sharing your own skills, background and experiences here in this great symposium, but to carry your message right through into those areas where these major decisions are made. And don't forget the wonderful words of Hubert Humphrey when he said that ultimately, the moral test of a government is how that government treats those who are in the dawn of life, the children; those who are in the twilight, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped.

Eli Goldstein Award Laureate Acceptance Address

by Senator Mark O. Hatfield

No disease is bearable, but clearly Alzheimer's Disease is merciless in its destruction of the human mind. What was once regarded as a normal consequence of aging has come to be recognized as a neurological disease that threatens the health and well-being of our entire society. Alzheimer's Disease affects 1.5–2 million people in this country. It claims the lives of 120,000 each year. The suffering endured by its victims is immeasurable, as is the emotional strain placed on families and loved ones. The cost to society in terms of medical expenses alone is conservatively estimated to be $12 billion annually by NIH.

As bad as all that sounds, consider the prospects for the future, when so many more of our citizens will be in the high-risk elderly age bracket. By the year 2030, it is estimated that more than 65 million people will be age 65 or older. From a humanitarian or economic standpoint—it is imperative that we act now to put a stop to this horrible illness. The victim is completely stripped of all mental and emotional faculties and becomes a prisoner within the human body but unable to carry out the simplest human activity. Our best hope lies in research aimed at uncovering just what causes Alzheimer's Disease. We certainly know more about the disease than we did 10 years ago, but not yet enough to find a cure or treatment. A major step forward was the recognition that Alzheimer's Disease is a neurological disorder—not a result of the normal consequences of aging.

We in Congress are doing what we can to help in this effort. The 98th Congress has devoted a substantial amount of its time and attention to finding out what medical science is doing to unravel the mysteries surrounding Alzheimer's Disease and examining how the disease affects its victims and its families. The Senate Appropriations Committee has held hearings on Alzheimer's Disease. We have heard very moving testimony, both from the medical experts and from family members. The Committee directed the National Institutes of Health to provide a comprehensive report. We asked to be informed on research progress (state of the science) and what efforts were under way to coordinate the work being done at NIH and other government agencies, such as the Veterans Administration. I like to think that our involvement set off a chain reaction that will bring us much closer to finding an answer to this dreadful problem.

Shortly after we received the report on Alzheimer's Disease, HHS Secretary Heckler announced her plans to create a task force to coordinate government research activities and to develop a comprehensive plan for attacking the problem.

Furthermore, other congressional committees have turned their attention to this matter. In May, the Senate Labor and Human Resources Committee held extensive hearings on the research aspects of the disease. Senator Hatch and his Committee have proposed legislation that is intended to bolster the level of research being conducted and to increase the level of Congressional oversight of government-wide efforts in this area. Similar action has been recommended by our colleagues in the House (Committee on Energy and the Environment). In July, Claude Pepper and others on the House Aging Committee begin to examine some of the problems associated with providing long-term care for Alzheimer's victims. The Senate Aging Committee is also looking into this issue. Finally, several Members in Congress have expressed concern, which I share, over the fact that Medicare does not cover this disease because the care that is given is regarded as custodial in nature.

Since 1976, the amount of government funds spent in this area has grown from $3.8 million to $22 million. The Appropriations Committee has recommended that this high level of funding be continued. Major Department of Health and Human Services research activities are in NIMH, Alcohol, Drug Abuse and Mental Health (ADAMHA), NIA, and National Institute of Neurological and Communicable Disorders and Stroke (NINCDS). Related research is also done by National Institute of Allergy and Infectious Diseases (NIAID). The 1983 estimate for research by these four is $22.34 million.

One major source of assistance (other than financial) to Alzheimer's Disease patient's families is the Alzheimer's Disease and Related Disorders Association, which was formed in 1979 and now has over 60 chapters throughout the country. A number of witnesses at Congressional hearings have noted the enormous psychological and social support they have received through this organization. ADRDA also provides educational and informational materials, and funds some small grants. There is great need for more research on the needs of families and on how to help families cope with Alzheimer's Disease, which imposes an enormous emotional and financial burden on them.

Even though there is no treatment for Alzheimer's Disease, there are two drugs which are being looked at and show some interesting early results. Press reports of their potential as treatments have unfortunately been exaggerated. The drugs, still in early research protocols, are naloxone and physostigmine.

There is a great deal yet to do, as I have indicated. The problem is not going to disappear unless we have a strong sustained commitment on the part of every facet of the community . . . government and private sectors alike. It might well be a protracted battle. But let us keep in mind the words of Hubert Humphrey who said that: "The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped."

Caring for the Alzheimer's Disease Patient—A Communal Response

The Role of the Family

by Rose Dobrof, D.S.W.
Director, Brookdale Center on Aging
Hunter College
Panelist

There is a particular appropriateness to this occasion which I must make mention of before getting to the subject of my paper. This audience is surely aware of the position the Hebrew Home occupies in the field of long term care: it serves as an exemplary model in the United States and internationally. This symposium on Alzheimer's Disease and Related Disorders; the recent acquisition of the facility which will serve as a treatment and research center on Alzheimer's; and the linkage of the Home and the Albert Einstein College of Medicine all demonstrate the leadership the Home is presently taking in the struggle against the blight of Alzheimer's Disease.

The role is not a new one for the Home, however; today's event is part of a historical continuity, linked to the Home's aspirations for the future, to be sure, but connected also to its past accomplishments. It is this heritage of accomplishments that make this occasion so exquisitely appropriate, and the record of today is not complete if it does not include citation of the past. It is now more than two decades ago that the late Alvin Goldfarb, a pioneer in geriatric psychiatry, first began calling the attention of his colleagues, public officials, and others to the increasing numbers of mentally-impaired older people who were being cared for in the Homes for the Aged and nursing homes in our state.

Dr. Goldfarb saw this as an inevitable and not inappropriate development: his concern, however, was for the quality of care that was being provided in the Homes for the Aged and nursing homes. A series of studies he did provided the factual basis for his concern: he found that staff of these homes often did not recognize the existence of mental impairment among the old people in their care; and that even when they did, they had little knowledge about treatment methodologies, environmental design, staff-patient ratio, etc.

Alvin knew that it was the bench researchers who would ultimately find the paths to prevention of mental impairment, but in the meantime, though he thought of himself as a researcher, he knew that the payoff of the work of the researchers would count for little in the lives of old people, already impaired, and their families and the professionals and other staff who tried to help them. His essential humanism required that he concentrate on the here and the now; that he respond to the needs of those who came to him for help. He had come to know the excellence of this Home under the leadership of its then new executive, Jacob Reingold, and its Board of Directors, including its current president, Irving H. Stolz, and it became the locus of some of his most substantial work. The staff training program he developed; the fine-tuning of his assessment instruments; his writings on the nature of the therapeutic relationship; his attention to the families of the mentally impaired and to the stress they experience—all of these were elements of the work he did here. The work reflected the particularly creative collaboration between the staff and Dr. Goldfarb, and it was important in establishing the Home as a model of the proper linkage between research, education, and clinical practice. It is this historical continuity—this connection between the work of the past, the accomplishments of the present, and the aspirations for the future—which makes today so appropriate an occasion and which should be for the Board and staff of the Home both a source of pride and strength and a standard against which to measure the deeds of today and the goals for tomorrow.

And now to our work. I should like to suggest three themes for your consideration: first, that the American family continues to be a bulwark of strength for its aged members; second, that Alzheimer's Disease takes its toll not only in the life of the victim but also in the lives of family members, and renders the family itself and the individuals within it particularly vulnerable to physical illnesses, economic impoverishment and social and psychological distress; and third, that for the sake of the family as well as the old person, there must be a partnership between family and service system.

Now for the first theme, that having to do with the capacity of the American family to care for its aged members. Thankfully, when speaking to a group as expert and experienced as this, it is not necessary to trace the lines of inquiry which led from the sociologist Talcott Parsons' bleak view, in the post–World War II period, of the attenuation of family ties and the isolation of the old from their descendent generations, to the rediscovery in the 1960s and '70s of the vitality and capability of the American family. The family is battered and buffeted and challenged and wounded, and changed in important respects, to be sure. There are, for example, the rising divorce rates, declining birth rates, increasing numbers of dependent aged members, the alternative life-styles, geographic mobility, the purported narcissism of a "me, too generation," etc., etc. So the family is battered and buffeted and changing, yes, yet it still is the locus for at least three critical social functions: to serve as the matrix for relationships of love and interdependence between adults; for the raising of children; and for the care of the old when infirmities and illnesses and impairment make independent living no longer possible.

It is of course, this third familial function—the care of dependent aged members—which is the focus of our interest today, so now let me summarize briefly those aspects of the state of the knowledge which are salient for us.

First: that regardless of class or ethnicity or even the quality of the aged parent–adult child relationship now or in the past, the majority of Americans believe in and try to live by the Biblical injunction to honor their fathers and mothers. Most Americans believe that families have responsibility for their aged members who need help; in few families is there question about the existence of this responsibility, about the right of aged parents to rely on their children, or about the imperative that the children respond to their parents' need. Rather, the often agonizing questions families face have to do with what the behavioral articulations of that responsibility are, and with how that responsibility, once defined, is to be carried, along with other familial, work, and communal responsibilities.

Second, evidence from a number of studies provides systematic confirmation of what the families of mentally impaired older people know all too well: that there is a unique and terrible quality to the pain of families who must bear witness to the intellectual decline of a once proud and self-sufficient parent; that no event in the history of the family poses a greater threat to the mental and physical health of caregiving family members, can so tarnish and corrupt their relationships with each other, or so compromise the integrity of the family as a psychological and social system. What is it that makes Alzheimer's so uniquely assaultive? It is, of course, "the 36-hour day," which in itself can quite literally wear caregiving family members out. It is the behavioral changes, which are the manifestations of the disease; changes so profound that we can understand when the wife says to us "The husband I knew is gone" or the daughter says, "That isn't my mother anymore." It is the isolation and sense of alienation which can cast yet another shadow over a home already darkened by the blight of the disease. "Other people just don't understand what I'm living through," says one wife of an Alzheimer's Disease victim. "I spend my days feeding him, and taking him to the bathroom and dressing him and trying to keep him from getting upset. People don't want to hear about such things, but what else do I have to talk about?" And so old friendship ties are weakened; conversations become stilted and uncomfortable; days may go by with little contact with the world beyond the four walls; and just when the support and affection of others is most needed, it is least likely to be available.

What other factors contribute to the unique and terrible pain the family of the victim must endure? Probably the more general difficulty we Americans have with mental illness and psychological distress and intellectual impairment must be included in this calculus of suffering. We seem better able to cope with clear-cut, unambiguous physical illnesses than we do with the uncertain, frightening, changing character of mental illness or mental impairment—no matter what the age of the victim is, or the victim's status in the family.

Eli Savitsky wrote in 1972 that:

> "Family members more easily understand and accept physical illness than mental impairment or other psychological disorders. They see it more as a not unexpected fact of life and feel less bewildered as to its cause and course than they do about mental illness with its uncertain origin and unfamiliar, frequently frightening manifestation."

In relation to this point, I commend to you the two recent books by Joel Veroff and his associates—*The Inner American* and *Mental Health in America, 1957 to 1976* (New York: Basic Books, 1981). Veroff had been a member of the team of social scientists who in the late 1950's studied the attitudes of Americans toward mental health issues, and in 1960 published their findings in the seminal *Americans View Their Mental Health* (New York: Basic Books, 1960). They concluded then that:

> "People tend to externalize their problems, to locate them in 'concrete' material things..., to see them as reactions to external events...(There is a)...tendency for people in the general population to phrase their problems in nonpsychological terms...."(p. 49)

In 1976 they found Americans more likely now than they had been in the '50s to define psychological or relationship problems in those terms rather than in external and concrete terms. They found also that Americans today are more likely to seek help when psychological or relationship problems cause them distress. The researchers found American adults of today less likely than in the 1950s to accept such problems as their lot in life, to be endured without hope, instead of confronted and solved.

Despite these shifts in the years between 1957 and 1976, there remain in the United States attitudes and beliefs which make it difficult for some families to accept as a disease something whose presence is announced in behavioral terms, and in behavior which so frequently assaults the very souls of the spouses and children.

The philosopher wrote: Cogito, ergo sum; I think, therefore I am; and I suspect at bottom many Americans, even those who do not know these words and even many in this room, believe in the truth of this assertion. What defines our humanness and separates us from all other living beings on this earth, we believe, is that we think; we plan; we remember; we calculate; we build theories; we accumulate knowledge. Cogito, ergo sum; I think, therefore I am; and when I no longer can think, when my intelligence is gone, then my personhood, that which I am, is gone.

This, I think, is what the wife means when she says the husband I knew is gone, and this necessity to respond to, care for, look after a human being now robbed of that which defined him as a person, this I think is at the core of the pain families experience—it is this which makes them so vulnerable and which can tarnish even the most faithful and loving relationships.

One more dimension of the pain families experience—and this leads to my final point about the necessity for partnerships between families and service agencies and professionals. Alas, some of the pain is iatrogenic in nature—it is caused by the pathology in our health and social service systems, by the lack of responsiveness of large systems to individual need, by the holes in the service system, by the complexity of its rules and regulations. One of my colleagues, presently doing research on Information and Referral Services, says that when the families of Alzheimer's victims call Information and Referral Services for help, the primary characteristic of these families is their desperation. And the desperation comes not just from the recognition of the increasing impairment of the Alzheimer's victim—it is the desperation of families carrying a burden far beyond their capability and without help from the community in which they live. One 72-year-old husband, a man who had a proud record of service to his community, now is facing the awful reality of the disease's toll on his afflicted wife. He is frightened about how he is going to manage. His wife's physician couldn't give him any information about programs or benefits; he doesn't know where to turn for help; he isn't sure what he needs or what he's eligible for. No one seemed ready with both a listening ear and accurate, up-to-date information. So he's been carrying the burden by himself. "I worked hard in and for this community for 40 years, and so did my wife. And now it's like it's all wasted. Don't we have a right to make a claim on the community for help now that we need it?"

This man's sense of desperation and abandonment, I am saying, is iatrogenic in origin; it is caused by, and reflective of, the pathology of our fragmented, incomplete, and hard-to-reach system. It is, therefore, not an inevitable, intrinsic element of the disease, but an altogether preventable dimension of pain.

All of the research on family caregivers, including that of Brody, Shana, Sussman, Litwak and Gurland, among others, demonstrates both the willingness of families to perform caregiving tasks and the need of families for help from agencies and institutions on which they can rely and from professionals who understand and value the efforts of families to do what is right. In all of the model projects—the CSS Natural Supports program here, Florence Safford's work and that of Alida Silverman in Michigan—wherever there have been projects aimed at providing supports and services for caregiving families, the evidence has been clear that when services are provided to families, families do not respond by abdicating their responsibilities to the agencies. Rather, the provision of services—the partnership between family and agency, the sharing of the responsibility—enhances the capacity of the family to carry its share and shores up its ability to sustain itself and its members, even in the face of the continued decline of the Alzheimer's patient. Moreover, even if institutional care becomes the appropriate arrangement, the necessity for the partnership between Home and family continues. The mentally-impaired old people in this Home today who have the benefit of the care and services of the Home and also the concern and love of their family will have more than will the old person without family who, to paraphrase the playwright, must always depend on the kindness of strangers.

And when the death of the mentally-impaired mother or father comes, the children who have been able to be partners to the Home and continue to carry responsibility—if only to visit or to bring small necessities or to make sure all is well—these children will at least have the comfort of knowing that they did what was right; they did the best they could.

The family who must carry this responsibility alone, without help and without understanding, is a family at risk, and a society which continues to permit families to carry this burden without providing the help that they need is equally at risk. I hope that in our deliberations today and when we return to our appointed tasks tomorrow we do not lose sight of our responsibility to be good partners to the families who come to us for help.

The Role of the Institution

by Helene D. Grossman, M.S.
Associate Executive Director
The Hebrew Home for the Aged in Riverdale
Panelist

When I first arrived at the Hebrew Home in 1976, many individuals had a primary diagnosis of OBS—organic brain syndrome, but that was, and remains, a catch-all category with little meaning. Soon after that, we began to see a few new patients being admitted with a primary diagnosis of Alzheimer's Disease. These individuals were under the care of physicians who were either medically sophisticated or had sophisticated office addresses. This trend, though, was also short lived. Within a few brief years, even if the patient *had* Alzheimer's Disease, the diagnosis did not appear on the intake report. Families were afraid to tell us the diagnosis, for fear that the institution would not accept the patient. Some of these fears stemmed from policy issues related to concerns about Medicare reimbursement for an Alzheimer's patient. Other fears were based on the families' misconceptions about the disease process.

Alzheimer's Disease has become more fashionable again. The President proclaimed Alzheimer's Recognition Week. The National Institute of Mental Health is funding research into the causes and cures, and Alzheimer's Disease has caught the imagination of the media. We at the Hebrew Home are once again beginning to see more patients with an intake diagnosis of Alzheimer's Disease. Whether or not all of these new patients *are*, in fact, suffering from Alzheimer's Disease is still questionable. In fact, the diagnosis of Alzheimer's Disease may still be more a function of the referring physician than the patients' illness. *Some* of the patients being admitted to the Hebrew Home with this diagnosis have had complete diagnostic workups, others have not. While the institutional role is not one of diagnosis, it is the role of the institution to accurately differentiate patients according to their levels of need. It therefore follows that the *institution too* must stress the importance of accuracy in differential diagnosis.

Research has taught us to recognize that there are a variety of different dementias, and that senility is not a normal consequence of advancing age. We are even careful now to diagnose Alzheimer's Disease as S.D.A.T.—senile dementia of the Alzheimer's type (DMA-III 1981). This suggests that there is not one type of Alzheimer's Disease but a variety of subtypes. They may all result in similar symptoms, but may have somewhat different causes and courses. Inevitably, we will find that the various sub-types have different forms of therapeutic intervention. Presently being debated is the policy issue of custodial maintenance or active therapeutic intervention as the more appropriate mode of treatment for the Alzheimer's patient. As an institution, what role do we now take? Do we assume that SDAT is a universal illness, with one on-going treatment or intervention modality, and if so, what is the best type?

Over the years, long term care facilities have been caring for individuals with behavior indicative of dementia. The care, and the types of patients, however, have been slowly changing. There are now more older adults surviving to advanced age. Along with increasing age comes an increasing incidence of Alzheimer's Disease.

A related issue is this age factor. Long term care facilities tend to admit individuals over the age of 65. Alzheimer's Disease can, and often does, occur in individuals in their 50s. We are not yet clear on the differences, if any, between Alzheimer's patients in their 50s, and those in their late 60s or older. We tend to believe that younger individuals with Alzheimer's Disease are more ambulatory and fleet of foot, and hence, more difficult to care for. As a result, long term care facilities have generally shied away from accepting individuals of this kind. This approach may turn out to be a misconception but, here too, we still do not know enough about SDAT to respond in an educated manner.

With emphasis on providing more support to older adults in the community (GAO, 1982), those requiring care in a facility, will more likely be individuals who are difficult to manage outside of an institution. Institutions will have to respond to these individuals with a more structured and supportive environment. One example might include a physical activity and active exercise program for those patients who wander or have other physical needs of expression (Snyder, et. al., 1978).

The importance of individualizing care and learning to know who each individual person was, through psychosocial, cultural and spiritual histories, and then reviving whatever interest once existed through a variety of interventions, is recognized and emphasized.

The literature suggests that reality orientation programs are only moderately effective over the long term. The fact that they can be effective at all, indicates that different individuals have different needs, even different forms of the disease. Here too, we stress the importance of differential diagnosis, which will lead to a clear understanding of the best intervention strategy. To respond to this variety of need, the institution must be flexible in its support, and research-oriented in its approach.

We now know that patients with Alzheimer's types of dementia respond well to supportive environments and a variety of different sensory stimuli. We place large calenders on the units and teach our staff to remind patients the time of day, where they are, and even who they are. We use bright colors on the units and our recreation workers and therapists have the patients work their hands, arms, eyes and brain as much as possible. *Some* patients respond to this stimulation, *others* do not. Why this is so is one issue that can be explored in a long term facility. We struggle as well with such additional issues as restraints, incontinence and retraining, and the effects of multiple simultaneous drug therapies. Institutions, by virtue of their structure, can perform critical analysis of the impact, effects and costs of alternate programing with different categories of patients, and can provide a wealth of important information on both an applied and basic level.

Reality orientation, sensory stimulation and physical activity programs are all part of the services offered to patients in long term care facilities. Most of these programs are also offered to other patients in the facility. An interesting issue is raised by this. Often, demented patients exhibit behavior that other patients find annoying. As part of a study recently completed at the Hebrew Home, patients and staff were asked about some of their feelings regarding their unit of placement. In general, 80% of the staff interviewed said that it would be easier to perform their job, and patients would be more comfortable, if the patients were placed according to their type and level of care needs. Patients who were interviewed responded in the same way. They too reported that they would prefer to be on units that had other individuals with the same illness and level of care need (Salamon, 1983). By addressing this as an issue we begin to see that different patients have different levels of orientation and need for care. It is in institutions that these research issues can best be addressed.

It must be recognized, as well, that the staff of a long term care facility, particularly the hands-on staff, can be exhausted, frustrated and at times even frightened by the psychological aspects of Alzheimer's and the concomitant changes in personality and behavior. Staff education, on-going assessment of morale, peer and professional support as well as caring and nurturing to continue to do their jobs well are also viewed as an integral role of the institution!

There are other issues related to the role of the long term care facility in caring for patients with Alzheimer's Disease. The long term care facility is usually viewed by the family as the last option for care (Vladeck, 1980). There *are* programs, however, that suggest that facilities can provide an important service to individuals with Alzheimer's Disease in the community. Day care programs and facilities which provide respite services are some of the ways this can be performed. Others include providing support services for relatives who are caring for a family member at home who is suffering from Alzheimer's disease. Just providing a place for family members to meet is a useful intervention. The institution will no longer be foreign, or negative to the family. Family members will become more aware of the role of the institution and more open to the services provided there. The staff of the institution can work with the family, introducing them to the range of options available. When institutionalization becomes necessary, the family will be more comfortable with the transition and more aware of the course of the illness.

Research/Evaluation

Many aspects of Alzheimer's disease remain, . . . in Winston Churchill's phrase about Russia, . . . "A riddle wrapped in a mystery inside an enigma." Long term care facilities can fill leadership roles in the area of research and particularly evaluation regarding the variety of needs different patients present with, the assessment of those needs, successful programming interventions and constructive approaches to working with the family. If the institution is open to these possibilities it can provide a full range of services plus contribute to knowledge in a number of important ways.

The Hebrew Home for the Aged in Riverdale has developed an exciting set of plans towards this end which will be addressed by our Executive Vice President, Jacob Reingold, in the next session.

[1] [illegible]

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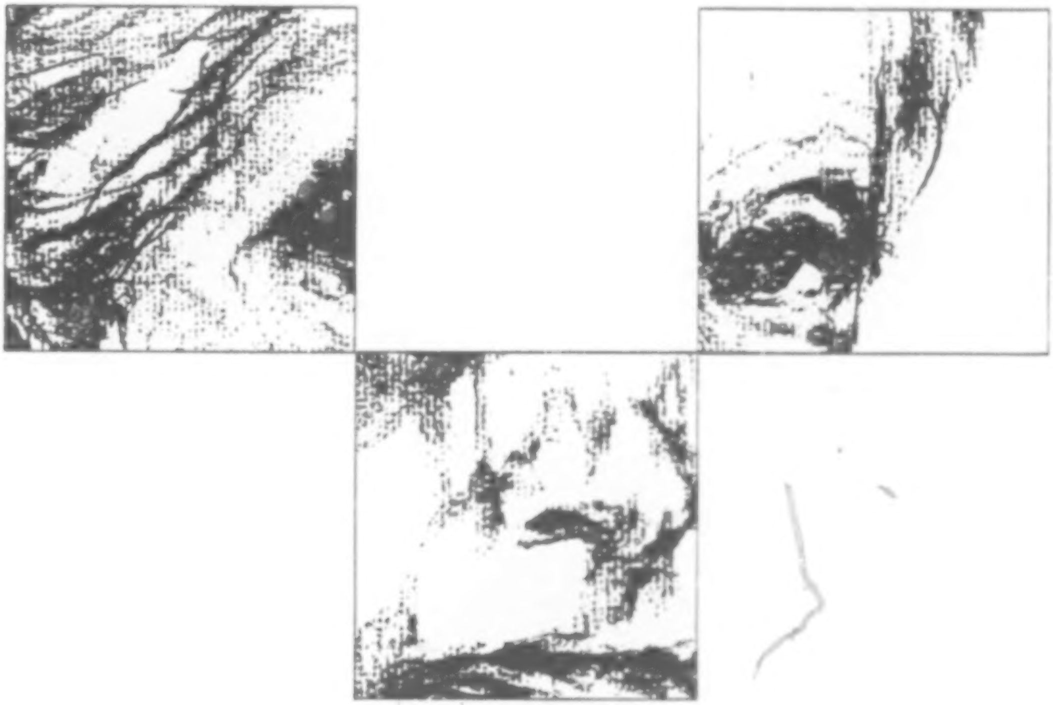

The Community as a Resource

by Janet S. Sainer
Commissioner
New York City Department for the Aging
Panelist

Although there are no exact figures on the number of persons who suffer from Alzheimer's Disease and related disorders, recent reports in *Science* estimate that from five to ten percent of those over 65 or as many as 2 million Americans are afflicted. Worse, as we conquer or ameliorate other illnesses, thereby extending the lives of individuals and increasing the number of elderly, the incidence of Alzheimer's Disease rises. It is projected that the prevalence of these illnesses will more than triple in the next 50 years.

Up to now those who are afflicted by Alzheimer's Disease and those who care for them have tended to close themselves off, to cope silently with little help, except from those in the institutional field. Until very recently Alzheimer's Disease has been viewed as an institutional rather than a community-based problem.

However, by the most conservative estimates, at least a million Alzheimer's patients are maintained at home. In New York City there are probably upwards of 50,00 persons over 65 living in the community who are afflicted with Alzheimer's or similar disorders.

We are well aware that a diagnosis of Alzheimer's Disease changes the life of the entire family for as long as the patient lives. Recent studies indicate that most families maintain their relatives at home for four to eight years. Families are caught in the dilemma of increasing demands and decreasing resources. Progressive deterioration and unpredictability of symptoms force the patient and the family to adjust continually to new problems and higher levels of impairment.

Clearly, until we achieve a major breakthrough in research to prevent the onset of Alzheimer's Disease and other related disorders, an urgent need exists to develop programs and services to assist families who can care for their stricken members and humane services for those who have no families. Moreover, we must be sure that quality services are available, accessible and appropriate; that there is widespread public education about the enormity and complexity of this problem, as well as knowledge of programs that can alleviate the physical, financial and emotional strain placed upon patients and their caregivers.

One of the major resources for caregivers is the family support groups which are springing up across the country, supported by local agencies, major hospitals and chapters of Alzheimer's Disease and Related Disorders Association (ADRDA). These groups strengthen the morale, well-being and treatment skills of care providers; they are also alerting the community to a serious social and health problem. ADRDA is a nationwide organization with over 80 chapters and is dedicated to fighting Alzheimer's Disease and informing the public through newsletters, educational forums and family support groups. Moreover, they serve as a resource for families seeking guidance as to where to turn for help.

Since as many as 30-40% of people with symptoms of dementia have a correctible disorder, an essential first step is receiving an accurate diagnosis.

In New York City, in addition to competent private practitioners, there are four renowned Alzheimer Diagnostic Centers: Milhauser Labs at New York University Medical Center, Albert Einstein College of Medicine, Bronx V.A. Medical Center and Mt. Sinai Geriatric Clinic. In addition to providing diagnostic workups, they offer a broad variety of services to patients and their families and can make referrals to home care agencies, social services and financial counselors, and provide family support groups.

Once a diagnosis is made the caregiver is faced with the task of arranging for care and supervision of the person and property in order to maintain the patient at home as long as possible. Assuredly the proper administration of home care for an Alzheimer's patient is an enormous task. Presently the city's Human Resources Administration provides three types of publicly supported, home care assistance for those who meet the income eligibility criteria: *Housekeepers*: Duties include housekeeping, laundry, shopping, escort and meal preparation; *Homemaker/Home Attendant*: Duties include the above plus limited personal care, grooming and feeding; *Home Health Aides*: In addition to homemaker responsibilities, health related tasks such as overseeing medication, changing dressings and bathing assistance are provided.

For those who are just above Medicaid Eligibility, the Department for the Aging provides in-home services on a limited basis, as well as escort services, friendly visiting and telephone reassurance—all aimed at assisting the elderly in the community. In addition, the Department is responsible for administering the total Home Delivered Meals Program in New York City, which currently provides meals five days a week to 6,000 homebound elderly.

Despite what may appear to many to be very limited services, it must be noted that New York City as the largest home care program in the nation, serving 38,000 homebound individuals. In order to be eligible for this program, the client must be Medicaid eligible and capable of directing and supervising the home attendant or have family available to provide the supervision.

The Medicaid income eligibility in New York State is now $4,000 a year for a single person and $6,400 for a couple. Assets can only include $2,700 for one person and $4,200 for a couple, plus $1,500 per person for a burial fund.

At this time only about 17% of New York City's elderly are Medicaid eligible. The large majority are not. However, lack of Medicaid eligibility does not necessarily ensure one's ability to pay for needed services and care. Most recent income data for the city's elderly indicate that half of those 65 and over have incomes falling between $4,000 and $10,000. Families and individuals requiring full time help may have to pay between $250-$400 a week. Certainly not many elderly or their families can support such costs. Unfortunately, our current system not only overburdens adult children who assume responsibility for their disabled relatives, but can pauperize the caring spouse.

If the community is to be a true resource, then a continuum of care from in-home services to institutional care must be provided. I believe that Medicare must be expanded to include long term care services, and not just acute care. In that way in-home services for the chronically disabled, such as Alzheimer's patients, would be financed under Medicare. If Medicare is not expanded then society will be paying for increased lengths of stay in hospitals or sending patients to nursing homes when such care is not needed.

The current staggering costs of long term illness also raise serious legal questions. Most people think that estate planning implies planning for the distribution and management of an estate at death. In the case of the Alzheimer's victim, the difficulties as well as urgent necessities for planning for the living but incapable person are dramatically illustrated. Early in the onset of the illness it is important to ensure that any funds in the name of the victim will be best used for his or her care and that the remaining family members be provided for.

There are several legal resources open to families of individuals with dementia. The Hunter-Brookdale Institute on Law and Rights for Older Persons can provide advice on areas such as obtaining power of attorney, conservatorship or representative payee. Families can also turn to the Older Americans Act Legal Services Programs, sponsored by the Department for the Aging, which offer free legal assistance to senior citizens in four boroughs. In addition, the Department's Central Information and Referral Unit can offer advice on services and entitlements, find the proper source of assistance in the community and ensure that those who are eligible for benefits have access to them. Social workers at senior citizen centers and social service organizations can assist the family with the filing processes for whatever benefits and reimbursement might be available.

Other public and voluntary agencies can offer services which can be helpful. To reiterate, home care services can be obtained from both the Human Resources Administration and the Department for the Aging; the Department of Mental Health, Mental Retardation and Alcoholism Services sponsors geriatric mental health clinics. Some of the New York State psychiatric facilities operate mobile geriatric teams; the Police Department can be instrumental in locating a wandering or missing Alzheimer's victim; housing project personnel may be the most regular contact in the resident's life and hold vital clues to the progression of the illness. In addition, the voluntary agencies in the home care field may offer important, concrete services, as well as emotional and financial counseling; local churches and synagogues can offer strength and understanding.

Consistently, a major need identified by family caregivers is for some form of relief or respite from the pressures of caring for their disabled relatives. Respite care can be provided either during the illness of a family member or when a break is needed from the care. Some skilled nursing homes (for example the Visiting Residents Program of Metropolitan Jewish Geriatric Center in Brooklyn) provide short term stays (from 1-6 weeks) in their facilities. The patient, however, must be medically eligible for a health related or skilled nursing level of care. New York State is presently funding a number of respite model projects which provide medical, nursing and personal care, as well as recreational services.

Adult day care and day hospitals represent another means by which caregivers can be given time off with the security of knowing that a patient is receiving care from a dependable and trained source. Such programs offer services ranging from active rehabilitation to social and health related care. Adult day care programs for persons with Alzheimer's Disease and related disorders are scarce and may be a more appropriate system of care for patients at the beginning stages of the disease. The only adult day care center in New York City established exclusively for Alzheimer's patients is the International Center for the Disabled Service Program for the Aged. Reality orientation is the focus of its treatment and a day program is provided four days a week for patients, with counselling and support services offered to family members. Day hospitals are designed for rehabilitative purposes and are operated by a medical staff of doctors, nurses and therapists. In order to be eligible patients must not require 24 hour care, but have health needs that cannot be met adequately at home.

In the case of both respite and day care, Medicaid is the only full reimbursement mechanism. Private participants can find the cost of service prohibitively expensive as well as unavailable for many Alzheimer's patients.

In addition to model projects aimed at testing the effectiveness of respite care, it seems timely that we begin to look at alternate living and service arrangements for long term care patients who require custodial care. Such patients could be housed in close proximity to each other, with case management, home care, group shopping, meal preparation, and assistance in money management. The State's Enriched Housing Program attempts to provide some of these services for the frail elderly. Perhaps the concept of enriched housing might be applicable to illness like Alzheimer's where memory and judgement prevent the patient from directing a personal care worker, and more comprehensive services are required. Marion Roach, author of the article that appeared in *The New York Times Magazine* "Another Name for Madness" suggested that a communal living situation be established, whereby a small number of patients are housed in the same apartment, receiving centralized supervision and services.

Undeniably, Alzheimer's is a progressive disease and nursing homes must be viewed as an important and frequently needed option in the continuum of care available to victims and their families. Locating a nursing home which will accept an Alzheimer's victim can be a difficult task. Lists of institutions, how to apply, rights of patients, etc. can be obtained from the Friends and Relatives of the Institutionalized Aged (FRIA), the Long Term Care Nursing Home Unit of the Department for the Aging, or the Association of Homes for the Aged.

As we experience the "aging of the aged" and view the current and projected increase in the number of those over 85 years, the shortage of nursing home beds in New York State will become a more pressing issue. Institutions are an integral part of our community and if we aspire to be a just society then we must ensure that all our institutions are open to the most needy and disabled members of our population. The availability of nursing home beds must reflect the relevant demographic changes and the projected incidence of Alzheimer's Disease. It is possible that the creation of increased institutional resources may be more cost effective than the present expenditure for hospital back-up. Institutional resources should be architecturally appropriate and be staffed by persons specifically trained to meet the unique care needs of dementia patients.

New York City is an urban community, and like other urban areas throughout the country, has seen significant changes in its elderly population over the past ten years: it has grown older and it has become increasingly live-alone. The 75-84 year cohort rose 15 percent from 1970, while those 85 and over increased by 37 percent. In addition, the number of elderly living alone increased by 13.4 percent in the past decade. Clearly, more and more of our aged are kinless and mateless—they are the very old, the very poor, and usually female. Moreover, the lives of urban elderly are different from those of their counterparts elsewhere. They are apartment dwellers and many live in communities which have undergone enormous change in the past ten years. Their private doctors are growing older and are not being replaced by new physicians. Thus, there is often no doctor who knows them personally and who can recognize the subtle behavior changes that herald the onset of a deteriorating condition. The neighbors of the elderly who live alone are frequently casual acquaintances and younger people who also may not be aware of changes in the older person until some overt act, such as turning on and forgetting the gas or letting a tub overflow, occurs which threatens not only the older person but his or her neighbors. Our department is all too familiar with calls from landlords, housing project managers and the police who have identified these potential patients and are seeking assistance on their behalf.

Families cannot shoulder the responsibility of caring for an Alzheimer's patient alone—this requires a societal commitment for care. As a community we need to expand our attempts to meet the very immediate needs of Alzheimer's patients and those who care for them. Perhaps by providing the vital day-to-day support needed we can lessen the tragic impact of this disease.

It is a truism that "the elderly of today cannot afford to wait for a better tomorrow." The challenge of Alzheimer's Disease is before us and it is a challenge that we can no longer ignore. Those of us present today share a common concern and now we must work together for a common goal: to ensure that our concerns are translated into action, to ensure that in the future the phenomenon of a "36 hour day" will no longer be applicable in the discussion of Alzheimer's Disease.

Implications for the Future—Public and Private Initiatives

by Raymond Vickers, M.D.
Associate Commissioner
Chief of Geriatric Services
New York State Office of Mental Health
Chairperson

Before I have the pleasure of introducing my illustrious co-panel members, I would like to say something about where we are now so that the challenges on which their initiatives should be based are a little more clear to you. Listening to a series of programs as we have done today, it would be easy to think that we have done nothing about these challenges. But I want to say to you that what is being done in this country and this state is a very great deal. However, almost everything that can be said positively about our efforts has a "but" attached to it. And that's what I plan to point out.

No other country in the world spends so much on public medical care programs as the U.S.A.; *but* there is no system of public benefits that has so many barriers to benefits for mental illness. No other country spends as high a percentage of its national product on research; *but* no other country spends such a small proportion on medical research compared with the proportion spend on armaments research and development. No other country has a longer history (and this may be a surprise to you) of the adoption of the concept of geriatrics, a word which was coined in this country; *but* the A.M.A. has withheld the naming of the specialty of geriatrics for those practitioners who specialize in that area to this day. No other state than New York has more institutional beds (mental and nursing home) for the aged: *but* in no other state do they cost more to occupy. No other state has a higher percentage or number of its population resident in mental hospitals (forty-four percent of those residents are over the age of 65, many with Alzheimer's Disease); *but* in no other state do we hear a more clamorous demand to open more mental hospital beds to the elderly, especially those suffering from Alzheimer's Disease. Currently there are about a hundred thousand HRF and SNF beds; *but* 65 percent of those are believed to be occupied by people with Alzheimer's Disease and related disorders. This was the first state to enact the state legislation to authorize the Medicaid amendments to the Social Security Act, and except for one other state, it has more benefits under Medicaid; *but* continues to exclude persons with Alzheimer's Disease from some of the benefits such as eligibility for the C.A.S.A. channelling program. It was the first state to have a long-term home health care nursing program; *but* has failed to expand it to all areas of the state. New York is probably the first state to have over a hundred thousand sufferers of Alzheimer's Disease within its borders; *but* has no epidemiological data to record them.

* * *

I've been spending a very interesting time recently trying to find out what it must be like to be in the world of Alzheimer's sufferers. For instance, I often hear people say things like "father is now a stranger to us," but father says, "everyone is a stranger to me." And that must be for father a much bigger tragedy, because it involves everyone in his life. These people are strangers in a familiar land and if you want to try to think what that's like just recall the last time you committed the error of walking into the wrong room. Nearly everybody's done this at one time or another. And as you looked around and saw everything looking unexpectedly strange and somewhat unfamiliar, someone may have noticed you and looked at you aghast and somewhat threatened. That is something of the reception that the Alzheimer's person suffers continuously. A permanently unfamiliar world is the world of the Alzheimer's victim. And so as you go home you might have a little fantasy and pretend to yourself that you don't know where you are, and you don't know anyone you meet. This may remind you of some past occasions in your life when you've had those same feelings. In that way perhaps you can understand more meaningfully those who are feeling that way at every moment.

Federal Responses to Alzheimer's Disease

by John M. Cornman
Executive Director
The Gerontological Society of America
Panelist

I. The Need to Think in Multiples

For the past five or six hours you have heard from an impressive array of experts on the state of knowledge about Alzheimer's Disease and related disorders. The presentations have run the gamut from research into causes, to problems of diagnosis, to difficulties of securing quality and affordable care, to moral and ethical problems raised by the disease, to the need for family support. I believe I could make a persuasive case that five hours of such presentations is about as much, if not more, than most of us can usefully absorb, and that this next 75 minutes might better be spent individually mulling over some of the sobering data offered us. However, unable to secure in advance the agreement of the chairman and other members of the panel to offer a period of silent meditation, I have prepared some broad thoughts on what necessarily must be a broad theme—implications of what we've heard for initiatives by the federal government. In doing so, I proceed on the assumption that, given the earlier presentations, there is no need to document here the awful human and financial impacts on individuals and families if the number of Alzheimer's sufferers increases as projected, or the ethical and moral dilemmas the disease creates for patient, family, caregiver, and lawmaker.

My purpose, then, will not be to justify the need for federal initiatives or to lay out a detailed program which the federal government *ought* to launch. Rather, I will offer examples of some choices and some factors which may affect those choices which ought to be considered in fashioning a federal response to Alzheimer's Disease, and will suggest some candidates for immediate consideration. If my remarks turn out helpful, they will do so not because they break new ground, but because they will indicate the need for a political framework in devising, promoting, securing and implementing a federal response to Alzheimer's.

No matter how sure we are of the moral or economic righteousness of our cause, politics will and ought to determine the shape of federal policies relating to Alzheimer's Disease. Clearly, the use of the verbs "will" and "ought to" suggests that politics, in the context of these remarks, is viewed at worst as a necessary evil and at best as the way society makes decisions in conflicts created by competing but legitimate claims on limited resources.

Two recent events brought home the difficult choices involved in just deciding how to spend federal biomedical research dollars:

- At a House Appropriations Subcommittee hearing, the group preceding the Gerontological Society was an organization formed on behalf of sufferers of and parents of sufferers of epidermolysis bullosa, a skin disease which afflicts young people. The condition, for example, can make the skin of the throat so sore the sufferer cannot eat. The group of testifiers, which included children with the disease whose spirit of determination should be an example for us all, were asking, much like Alzheimer's family support groups, if anyone were listening to their cries for help, and for money to fund research on preventing or treating the disease.
- An ad hoc organization formed to advocate increased federal funds for biomedical research listed heart disease, cancer, diabetes, arthritis and water-on-the-brain, as well as Alzheimer's, as deserving of continued and expanded research.

And, of course, the federal budget for biomedical research must compete in a broader arena, just as do the non-biomedical programs designed to deal with issues created by the increase in Alzheimer's Disease. So as we seek to design and have implemented federal responses to Alzheimer's Disease, we must think in multiples, about the political milieu in which we work, the range of concerns which deserve consideration if not action, relationships of these concerns to other aging and national issues, and the effects new knowledge will have tomorrow on whatever programs may be started today. Rest assured I am not about to explore all the options and nuances included in each of those broad areas, but I hope to offer enough examples to remind us, if that is necessary, that, with apologies to the poet John Donne, no issue "is an island."

Before proceeding, however, I would like to offer a caveat. As we have heard, relatively little is known about Alzheimer's Disease. "There may be as many as 100 conditions which mimic the symptoms of Alzheimer's Disease,"[1] and indeed, Alzheimer's may have more than one cause and may turn out to be more than one disease. Therefore, in terms of research, we should not anticipate discovery of a single treament; and in terms of care, we should be concerned with all conditions resulting from mental impairment, whether or not the cause turns out to be Alzheimer's. Progressive, irreversible mental impairment, regardless of cause, warrants sympathetic care and creates identical problems for caregivers. Therefore, just as physicians are urged to be cautious in diagnosing the disease, we all ought to be careful not to create false impressions when discussing the disease. Consequently, in this paper "Alzheimer's Disease" is used generically to encompass both general symptoms which may appear to be Alzheimer's and specific conditions of the brain discovered by autopsy, which is the only *certain* way to diagnose the disease.

II. The Range of Concerns

The range of federal concerns or activities prompted by the increase in the number of Alzheimer's sufferers can be said, for purposes of this discussion, to fall into three categories: biomedical/clinical, care, and family support. In each category, there is a need for research, education, and, in some cases, ongoing service delivery programs.

For example, under biomedical/clinical, we do not know the cause of Alzheimer's and the diagnosis is difficult, costly, and certain only after death. Those two facts alone suggest the need for a broad-based biomedical/clinical research program able to pursue multiple leads in the search for treatment and/or prevention, and affordable procedures for accurately diagnosing the disease. As research develops knowledge about the disease, it is important to translate and transmit that knowledge to appropriate practitioners. And, depending on how the art of diagnosing the disease progresses, it may make sense to establish an ongoing program to assist practitioners in diagnosing Alzheimer's.

Under care, we need to know more about how caregivers (whether family members or professionals) should act to lengthen the time persons with Alzheimer's can function, the comparative costs of different kinds of care, what kinds of institutions are best equipped to handle Alzheimer's patients at what stages of the disease, and how many of what kinds of facilities to build at what cost to whom to care for the increasing number of Alzheimer's patients. Depending on the results of such investigations, helpful results need to be translated and transmitted to caregivers and to decision-makers who will have to decide whether, for example, an effort similar to the Hill-Burton hospital construction program is needed.

Under family assistance, in addition to the need for knowledge relating to the delivery of care mentioned above, we need research to tell us more about the financial, physical and mental strain Alzheimer's Disease puts on families, and what kinds of assistance, at what costs, can help alleviate those adverse impacts. Again, depending on the answers, the information must reach counselors, professional caregivers, community leaders, and family members, as well as those who will design and implement programs to provide relief.

It would be easy to expand this list, but even this brief, cursory review indicates that Alzheimer's, like aging, requires a broad, interdisciplinary response.

III. Political Milieu

However one feels about $200 billion federal deficits, the economic policies of President Reagan, or restructuring federal-state-local responsibilities, I think we can agree that the nation is in a process of sorting out priorities, a process made more difficult by a realization of limited resources. Legitimate claims on those resources abound, and, added together, far exceed the resources available—or at least, the resources our society presently is willing to make available.

How that priority-sorting process works out will determine the political milieu in which the claims created by Alzheimer's Disease will be weighed and honored or rejected.

On the question of the proper role of the federal government in our society, proposals to provide federal assistance to families of Alzheimer's Disease run counter to the view that families and/or the voluntary sector should assume such burdens. It may be instructive that the chairman of the Senate Agriculture Committee was quoted this past week as stating that churches were not meeting their responsibilities in combating hunger, which suggests a preference for soup kitchens over federal food stamps or financial assistance.

On the question of federal spending priorities, proposals for major new expenditures on Alzheimer's Disease-related programs become part of the "guns or butter" debate, with the recent actions of the Soviets being used to support the former. One can argue, with justification, that for many families seeking to pay the costs of caring for an Alzheimer's patient, the choice is not butter or no butter, but financial independence or poverty. Whether that argument can be heard amid demands for MX missiles, nerve gas, jobs programs and education loans remains to be seen.

On the question of domestic spending priorities, funds for Alzheimer's programs could become a victim of a potential intergenerational competition for public resources, a possibility encouraged by those who suggest an aging population is a burden our society cannot afford.

On setting health care expenditure priorities, efforts to use federal health insurance programs to provide assistance for the costs of caring for an Alzheimer's patient run counter to the federal government's desire to contain its Medicaid and Medicare costs. Similarly, assistance through tax credits/deductions could be of concern to those worried about the size of the national debt.

In setting research priorities, tensions between funding basic and applied research increase as costs increase and budgets tighten, with those approving funds tending to favor the latter which promises to produce visible results sooner. In the instance of Alzheimer's, a strong case exists for basic research in the search for prevention, treatment, and diagnosis, *and* for applied research to improve diagnosis, care, and family support mechanisms.

It would be easy to expand this list, but even this brief, cursory overview indicates the impact the political milieu will have on the selection of federal responses to Alzheimer's-like diseases.

IV. The Impact of New Knowledge

It wasn't so long ago that "senility" was considered a normal condition of growing old. Now we understand senility is not "a normal part of growing old; in fact, it is not even a disease."[2] "Senility," it turns out, is a collection of symptoms caused by a number of different diseases, including Alzheimer's. As a result of this discovery, we are now embarked on searches to find ways to prevent and/or cure diseases which cause symptoms we used to think were unavoidable results of aging. I can think of no better way to describe the impact of new knowledge on directions of research, service delivery and family assistance policies. Clearly new knowledge affects the policy options as well as the political milieu. The recognition that diseases cause mental impairment among the elderly, for example, both defined a need for research and helped create a political milieu supportive of such research. Of course, new knowledge continues to—or should continue to—affect policy options until an issue is solved or, for whatever reason, disappears from the national agenda. In the instance of Alzheimer's, for example, discovery of prevention or treatment could alter projected needs for financial assistance and 24-hour care. Such discoveries could create a need for research on how to remove the cause, if environmental, or how to make the "prevention" or treatment widely accessible. If either were expensive, the case for financial assistance could switch from care to treatment. The policymaker needs to keep abreast of research lest new knowledge makes current policy options obsolete. It is not rare to find that in the time taken to devise and implement a public policy the problem has changed if not disappeared.

Interestingly enough, sensitivity to the impact new knowledge can have on policy options brings me back to the discussion of the range of concerns raised by Alzheimer's. In the quest for "answers," do we put our research resources into basic and/or applied research in biomedical, clinical medicine or service delivery investigations? Should research be directed at specific problems or diseases; and/or at general topics, such as aging; and/or at targets of opportunity created by new discoveries? Who decides and how? Each area of investigation is important, and discoveries in each area could affect public policies in the future; each approach to research is valid, and discoveries resulting from each can affect public policies in the future. The Congressional Office of Technology Assessment feels the answers to such questions are important enough to warrant a major investigation, scheduled to be completed early next year.

It would be easy to expand the list of potential impacts of new knowledge on federal Alzheimer-related policies, or to expand the list of choices facing research policymakers, but even this cursory review indicates the need for flexibility in devising federal initiatives in this area.

V. Some Conclusions

Thus far, I have posed questions and offered no answers. However, by joining those questions with my opening assumption that previous presenters have documented the extent of adverse economic and personal impacts expected if the number of Alzheimer's sufferers increases as projected, it is possible to offer some concrete recommendations for federal responses to be pursued promptly.

Alzheimer's has been described as a disease which starts out as the patient's and ends up the family's. Because it does, the disease requires a multi-faceted response, involving development of family care and financial support mechanisms as well as biomedical and clinical research. In devising that response, attention should be paid to what is not known as well as to what is known.

We do not know its cause or how to prevent or treat the disease. The projected growth in the number of persons expected to have Alzheimer's and in the costs of caring for persons with the disease, and concern for stress placed on the families of Alzheimer's victims, justify federal support for research seeking the causes of Alzheimer's and ways to prevent or treat the disease.

Because we do *not* know how to diagnose the disease accurately and because it has been projected that up to 20 percent of persons believed to have Alzheimer's may have different and, in some cases, treatable disorders, the federal government should support programs to develop and promote "excellence in diagnosis and delivery of clinical services"[3] for persons believed to have the disease.

We *do* know that families, despite major life-style changes, continue to provide a major portion of care for the mentally impaired elderly, including Alzheimer's sufferers, that the mental and financial burdens of providing this care cause serious strains if not destroy the stability of many of these families, and that existing federal health insurance programs do not help these families meet the expense of providing home care or of placing Alzheimer's patients in institutions when home care is no longer possible. Based on that knowledge, the federal government should encourage development of family-focused services, including day care, in-home household help, personal care services for the patient and respite service for caregivers. Further, federal health insurance programs should be adjusted to help pay the costs of home care for and institutionalization of Alzheimer's patients. The costs of *not* providing such assistance were summed up by Elaine Brody, Director of the Department of Human Services at the Philadelphia Geriatric Center:

> "If social policy does not move to mitigate these strains to the fullest possible extent by affording help to the families of Alzheimer's patients and other impaired older people, the ultimate costs will increase. The hidden costs now becoming visible—costs in terms of family strain and mental or physical breakdown—hold the potential for increasing the economic costs to the health and mental health systems. Both the social costs and the economic costs will be transmitted down through the generations."[4]

And finally, we know that federal responses to the challenge of Alzheimer's ultimately will be shaped by the political milieu and new knowledge. Those of us who believe Alzheimer's Disease and related disorders warrant a major federal response carry the burden of thinking in multiples as we promote our interest. Support for federal Alzheimer's initiatives will be affected by broad national priorities, as well as by priorities within aging. A single-purpose approach can create unnecessary competition for limited resources, or unjustly exclude persons needing assistance. We should work, then, for a broadly shared understanding:

- That the study of aging is not the study of the elderly alone, but of living, as important to each of us as learning how to eliminate hunger or to educate minds.
- That the study of Alzheimer's Disease and related disorders, which affects people of all ages, may unlock secrets about the aging brain from early in life through old age; and
- That in promoting particular "Alzheimer's" policies today, there is the need for policymakers and advocates alike to be sensitive to potential impacts of new knowledge, and to how those policies relate to other aging and national priorities and concerns.

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A Partnership

by Eleanor C. Friedenberg, R.N., M.S.
Deputy Director, Division of Prevention and Special Mental Health
National Institute of Mental Health
Panelist

All of today's speakers have identified and addressed the multiple dimensions of Alzheimer's Disease (AD)—medical, social, legal, and ethical. This panel addresses the implications for the future—in terms of initiatives called for by both the public and the private sectors. As we listened to today's speakers, there was a sense of being overwhelmed by the magnitude of the problem, and the experience of a sense of fear of the unknown—what is this disease—am I a candidate?

I experienced today almost a sense of split personality—I listened as a potential AD patient; as the family member (granddaughter) of an AD patient; as a nurse who has cared for AD patients; as a member of an agency staff at the National level involved in planning, program development, policy formulation, and research and training grant fund disbursements; and finally, as a private citizen in a local and State community. All of the various "Me's" need to get together in a partnership if any progress is to be made on the various dimensions of this disease. If there is any one message I would wish to call to the attention of this audience, it is the essentialness of the *shared responsibility* we have from the various perspectives we all represent. Without this shared responsibility, on a *planned* and *coordinated basis*, the implication for the future is simply "Wheelspinning." Let me give a few examples of what I mean. On the National level, a key element in policy, planning and financing is the Federal government—but, who/what *is* the Federal government? All of us act as citizens in the Federal government through our vote for congressional representation (legislative branch) and President (executive branch), and through our communication, as individuals and as members of advocacy/constituency groups, of our desires and positions on policy and legislation. To be effective for our purposes, there must be a partnership of the legislative branch, which writes the laws and appropriates the money, and the executive branch, which implements the laws and disburses the funds. It is all too easy for each to blame the other for failure to address certain areas. Present laws do not allow for costs of care for AD patients to be covered under certain benefit or entitlement programs—changing this situation requires a public/private initiative at all levels and a partnership of two branches of the Federal government in enacting and implementing new legislation. The importance of this issue at the Federal executive branch level is evidenced by the DHHS Secretary's Task Force on Alzheimer's Disease—membership is comprised of high level agency administrators, and the executive secretariat is the NIMH Center for Studies of the Mental Health of the Aging. This certainly supports the thesis we have heard today about the interactive organic/health and behavior/psychosocial elements of AD, with a major concern being the psychological impact on patient and family.

At the State and local level, the partnership is essential between the various service agencies—health and welfare most specifically—and requires a sharing of resources. This interagency collaboration has always been difficult to orchestrate, even in the best of economic times, let alone at a time of continuing fiscal constraints. Private groups and organizations, the networking of concerned private citizens, play an important role in monitoring or being a sort of nagging conscience to the public sector. The public sector has the difficult task of balancing the competing demands from the many private advocacy groups. From a research perspective—about which we have heard some exciting developments today—there is another public/private initiative and partnership which demands increasing effort. We are actually participating in that partnership today; public and private sector representatives have gathered to share information, learn from research findings which are funded from multiple sources (public and private), discuss ways of utilizing this research in many different settings, and honor a great public servant on behalf of a great private institution.

Another example of private initiative is the extensive research being funded by pharmaceutical companies in developing an effective drug in the treatment of AD. Granted, the company which succeeds in making a breakthrough stands to gain substantially financially, but this is a high risk venture for the private sector that will be of significant benefit to the public sector. In two weeks, NIMH is supporting the first national conference on research issues regarding the role of nursing homes in the care of the mentally disabled. The conference is being held in a private facility—The Hebrew Home of Greater Washington.

At the risk of digressing from the main theme of this panel, as I thought about the essential nature of the public and private sector "Partnership," I was reminded of another parameter of partnership which has been a favorite subject of mine for many years and about which we have heard a little today. My esteemed colleague, Rose Dobrof, and I have had many conversations about inter/multi-disciplinary collaborations—or partnership, particularly nursing and social work. I am struck today with the diversity of professional disciplines represented in this assembly—physicians, psychologists, sociologists, social workers, nurses, health care technicians, clergy, planners, administrators, managers—I'm sure I've overlooked a group and I apologize. The point is, it takes many different talents and fields of expertise for a comprehensive and effective program of research, prevention and service. If any single discipline were to attempt to "own" the problems of Alzheimer's, it would be *impossible* to solve the problem.

Implications for the Future?—Challenging, exciting. The problems are not insurmountable, but they require the concerned efforts of us all as citizens and professionals in the public and private sectors.

Meeting Tomorrow's Challenge

by Jacob Reingold, M.S.
Executive Vice President
The Hebrew Home for the Aged in Riverdale
Panelist

Alzheimer's Disease has emerged as a critical although not necessarily terminal illness that yearly afflicts half a million Americans. Senile dementia of the Alzheimer's type is a disease of catastrophic proportions. Now regarded as the major type of old age senility, it is a surprisingly common, although little known and understood, disorder that affects the cells of the brain. While experts formerly believed that Alzheimer's Disease occurred only in persons under age 65, this disorder is now recognized as the most common cause of severe intellectual impairment in older individuals. Whether the classic form of Alzheimer's Disease, which was first described in middle- aged adults, is identical in cause, mechanism, and course to senile dementia of the Alzheimer's type is a matter of controversy.

The major debilitating symptoms of Alzheimer's disease include serious forgetfulness, particularly about recent events, and confusion. At first, the individual experiences only minor and almost imperceptible symptoms that are often attributed to emotional upsets or other physical illnesses. Gradually, however, the person becomes more forgetful, to the consternation of anxious relatives. The person may neglect to turn off the oven, may misplace things, may forget whether he has performed a task or not, may take longer to complete a chore that was previously routine, or may repeat already answered questions. As the disease progresses, memory loss, personality changes, mood and behavior imbalances are likely to appear. Judgment, concentration, orientation, writing, reading, speech, motor behavior and naming of objects may also be affected. Even when a loving and caring family is available for support, the Alzheimer's victim is most likely to spend his or her last days in a nursing home or long-term care institution. At this time, there is no cure for Alzheimer's Disease and its causes are inadequately understood.

In working toward the creation of the Hebrew Home Alzheimer's Center, The Hebrew Home for the Aged in Riverdale is responding to a critical national and local need by developing a model for the comprehensive institutional care of the Alzheimer's victim. Using this 200-bed skilled nursing facility as a base, present Holland Care services will be expanded to provide teaching and research opportunities, care for the individual still living in the community, and family support programs.

Currently, placement in nursing homes in New York State is a function of patients and family as well as the predictor scores obtained on the NYS-DMS-1 profile. Pre-admission workups for individuals seeking admission to the Hebrew Home for the Aged in Riverdale's main campus also include a physical examination and a brief mental status evaluation.

For those applicants to the Hebrew Home Alzheimer's Center presenting symptomatology of organic or functional mental impairment, the critical processes of differential diagnoses will be employed. This will include a detailed history, a comprehensive physical examination, mental status and psychiatric evaluation and appropriate ancillary examinations. The latter category might also include: computed tomographic scan; electroencephalogram; complete blood count; metabolic screen; or DDRL. The goal of such specified diagnostic workups is to provide data for placement within a specialized long-term care setting, to develop an appropriate plan of care with realistic patient expectations and to provide meaningful information and counselling for the families.

The skilled nursing facility will provide care to any individual aged 55 and over with a primary diagnosis of mental impairment, either organic or functional. Specific units within the facility will be designed to address the progressive nature of the dementia syndromes. The facility will include a 10–15 bed locked, skilled nursing facility unit for the physically active and potentially abusive Alzheimer's patient. The units will be equipped with a gymnasium to encourage positive physical activity and counter-balance aggressive and abusive behavior. The facility will also include a 40 bed unit for the moderately mentally impaired with few physical infirmities. This unit will be designed as a therapeutic community, building upon the existing resources of each individual. Additionally, there will be a 10 bed respite unit for individuals with related diagnoses who will stay for average periods of 15 days, to provide a respite for their families.

The Alzheimer's facility will be designed to be environmentally and programmatically supportive. The use of chemical and physical restraints will be viewed as non-advantageous alternatives. Among supportive features planned for the facility are: color-coded rooms matched to the individual's ID bracelet; remotivation, reality orientation and resocialization classes and programs; physical activity as therapy, including a gymnasium; special and color-coded furniture; a quiet room; a psychiatrist as medical director; and psychiatric nursing staff supported by mental health technicians.

Given the unique nature of the Alzheimer's facility, prior to its opening a research program will be developed to evaluate staffing; the impact of various program options; the longevity morbidity; use of external hospital or specialty care required by the population; quality of life for patient and families; staff turnover and the cost of the various units compared to traditional skilled nursing facilities and State hospitals. Research with the Albert Einstein College of Medicine will provide complementary basic science information.

There is little doubt that the redesign of the Hebrew Home Alzheimer's Center will meet a significant community need. The ideal accessible location of this facility enhances its value as a community resource. Program plans for the facility to maximize community value might include adult day care for the mentally impaired population; an evaluation service for individuals currently residing in the community who are exhibiting symptoms of dementia in order to provide guidance and recommendations to their families; and an out-patient department.

The Hebrew Home Alzheimer's Center facility provides an unusual opportunity to our community to develop a model for the care of the Alzheimer's patient. Extension of our program through research and training opportunities provides potential for a significant contribution to the larger field of gerontology. This is an opportunity which the Hebrew Home for the Aged in Riverdale is eager to pursue; a challenge we are ready and willing to meet.

Criterion For Admission To A Specialized SNF Unit

To be admitted to this unit patients will meet the following criteria:

I. Cognitive:

Patient will have moderate to severe cognitive decline as indicated by one or more of the following:

1. Decreased knowledge of current and recent events - disorientation to time (day of week, season, etc.) or place.
2. Exhibits deficit in memory of one's personal history (e.g. age, year married, etc.).
3. Concentration deficit elicited on serial subtractions (backwards from 40 by 4).
4. Inability to perform, or follow through on complex tasks for functional reasons (dressing self, etc.).

AND/OR

II. Behavioral: (Observed and documented by staff)

1. Wandering into others rooms, being disruptive or intrusive, or,
2. Antisocial behavior - spitting, yelling, banging, fighting, undressing, or,
3. Injurious behavior to self or others.

AND

III. Physical

1. Physicians diagnosis of an Organic Mental Disorder, i.e.,
   - A. Primary degenerative dementia (DSM III 290.XX)
   - B. Multi-infarct dementia (DSM III 290.4X)
   - C. Alzheimer's Disease or SDAT, or

2. A diagnosis of a major psychosis with behavior as described in II, i.e.,
   - A. Schizophrenic disorder (DSM III 295.XX) or,
   - B. Paranoid disorder (DSM III 297.XX) or,
   - C. Bipolar disorder (with psychotic features) (DSM III 296.XX)

IV. DMS-1 Measurement

1. Patient must have a DMS-1 score of at least 180. (Scores are generally well over 300).
2. Total points for the mental status section will range from 85 to 210.

NOTE: Given the above behavioral/cognitive function, the patients considered for transfer will have a resultant need for greater and/or specialized assistance, support and care.

ASSESSMENT FORM FOR TRANSFER TO SPECIALIZED UNITS

1. DIAGNOSIS:

A. Organic Mental Disorder (Primary degenerative dementia, Multi-infarct dementia, SDAT)

____Yes ____No

B. Major Psychosis (Schizophrenia, Paranoia, Bipolar disorders with psychotic features)

____Yes ____No

Any Comment ____

2. BEHAVIORAL (Must have been observed and documented)

(Dates-Frequency)

			MD/Psych.	Nurses Notes	S.W. Notes	MCP
A. Wandering	____yes	____no				
B. Distruptive or Intrusive	____yes	____no				
C. Anti-social: spitting, yelling, fighting, undressing	____yes	____no				

3. COGNITIVE (Not necessary if "yes" to both #1 and #2; not necessary if "no" to both #1 and #2)

Notes

A. Disoriented to time ____yes ____no

B. Disoriented to place ____yes ____no

C. Deficit in memory of personal history) e.g. age, year married) ____yes ____no

D. Serial substractions (backwards from 40 x 4, document last correct in number in notes section ____yes ____no

E. Inability to follow through on complex tasks for functional reasons (holding a cup, dressing) ____yes ____no

4. This patient is ____ is not ____ recommended for admission/placement on a specialized unit.

Additional Comment ____

5. Total DMS-1 Score ____________ Points in Mental Status ____________

____
Date

____
Signature & Department of Person(s) Completing Form

Urinary Incontinence in Alzheimer's Disease

July 1986

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URINARY INCONTINENCE IN ALZHEIMER'S DISEASE

INTRODUCTION

Urine control may be defined as the ability to inhibit the passage of urine until an appropriate time. This requires several factors: integrity of the genitourinary system, the cognitive ability to adequately interpret and know how to respond to the sensation of a full bladder, a degree of mobility that allows the individual to react to the sensation of a full bladder, and the motivational basis to want to inhibit the passage of urine.

Few studies have specifically explored factors associated with urine control in Alzheimer's disease. However, urinary incontinence in old people, especially the institutionalized, is associated with impaired cognition.[8,15,36,39,40-41,57,61,73,75] Most studies did not distinguish between impaired cognition associated with chronic dementia, and irreversible deterioration in mental status, and acute delirium, a more sudden reversible confusional state.[39-41] Similarly studies that attempted to reverse incontinence did not distinguish between dementia and delirium. Rather their samples were specified as containing patients with chronic cognitive[18,41-43,64] or chronic mental patients.[16,30,31,45,46,57,68,78]

Some researchers did specify their samples more clearly. Sogbein and Awad did not find acute delirium in any of their incontinent subjects.[73] Hodkinson divided subjects into a mentally normal group, a group with a history of intellectual deterioration of at least three months, and a third group with a history of recent confusion.[36] He found incontinence to be related to mental impairment irrespective of the etiology of the mental impairment. One group of researchers stated 95% of their subjects evidence "age related" organic brain syndrome.[69] Another study found that in people 80 years or older who had dementia urinary incontinence was three and one half times more common than in those without dementia.[15] However, the cause of this cognitive dysfunction has not been reported and only rarely has the urinary incontinence been evaluated.[73,75] While there has been no specific study of urinary incontinence in Alzheimer's disease, its common association is accepted.

Prevalence and incidence of incontinence in Alzheimer's disease is not known. Reisberg and others developed the Global Deterioration Scale (GDS) for age-associated cognitive and Alzheimer's Disease and noted that incontinence might occur at stage 6, severe cognitive decline, and should be expected at final stage 7, very severe cognitive decline.[66] The 1977 National Nursing Home Survey described 7% of patients as having chronic brain syndrome with 58% of these noted to have incontinence.[77] This group may represent the institutionalized portion of these with final stage cognitive decline. Yet, clinical impression suggests that loss of urine control with cognitive impairment is not limited to late stages. National estimates derived from a large long-term care study reported 55% of patients incontinent, 54% disoriented, and 41% having inappropriate behavior.[60] The extent of these findings implies difficulties with urine control at earlier stages of cognitive dysfunction.

The lack of literature on urinary incontinence and Alzheimer's disease is thought provoking. One wonders if a pervasive hopelessness arises from these complex clinical entities to overwhelm researchers. In practice there is a tendency to dismiss incontinence associated with cognitive impairment, a coping attitude pervades with attention to urine containment at best. Yet basic clinical evaluation and attention to the environment might prevent or delay incontinence in almost all cognitively impaired elderly. These strategies in combination with treatment as medication and/or behavioral therapies should resolve or reduce wetting episodes. A best guess clinical estimate is that at least 50% of cognitively impaired elderly with loss of urine control could regain control with such evaluation and treatment. In reality, this figure is apt to be much higher. This paper will examine the etiology, evaluation, and treatment of urinary incontinence in institutionalized patients with cognitive impairment. Except for specific environmental features, this information is applicable to the non-institutionalized as well.

ETIOLOGY

RELEVANT FACTORS

A number of factors impinge on urine control, that is, they increase the difficulty of getting to the toilet to void without wetting on the way. Cognitively impaired elderly may be less able to cope with these bladder stressors.

Medications either prescribed or over-the-counter can alter urine control, causing frequency, large bladder capacity, or urinary retention with overflow.[10,47] Caffeine has a natural diuretic effect and is found in coffee, tea, cocoa, and some soft drinks.[1] Intake prominent in these liquids will increase urinary frequency. Fluid intake volume should average 14 to 20 milliliters per pound of adult body weight, e.g. 1890-2700 milliliters of fluid per day for a 135 pound adult.[81] Too little fluid will contribute to urinary tract infection and constipation/impaction, both associated with incontinence. Too much fluid will cause frequency and in some situations electrolyte imbalance and neurological disturbance.[74]

Accessing a toilet is a function of toilet location, patient mobility, and bladder voiding signals. A Scottish study recommended that toilets be within 30 to 40 feet of continent, mobile, mentally competent patients.[70] Hence, they should be very close to the impaired. The ability to rise from a chair unaided is facilitated by appropriate chair design. Usual recommended ranges for chair features include seat height 15-20 inches and arm height from seat 7-10 inches.[25,28,58] One study found that 77% of patients initially classified as chairfast were able to rise unassisted from a chair 17 inches high with chair arms 10 inches above the seat.[25] Although half the sample had some degree of organic brain failure, the chair design was least likely to effect mobility in those with the greatest cognitive and behavioral disability.

Toilet access is also facilitated if the path to the toilet is well lighted, distinguished by color contrast, and free of obstacles. Toilets must be clearly labeled; consideration should be given to painting toilet doors a special, noticeable color, e.g., all toilet doors are red. Cognitively impaired patients need all appropriate aids for independence in toileting. Hence, they should wear their prescribed eye glasses, derived from an adequate eye examination within a reasonable past time frame. Such glasses should be clean, and, for the institutionalized, labeled to avoid loss. Most often it is the cognitively impaired who are not wearing their glasses; yet, these are the individuals who most need all the aid possible. Attention would also be paid to cane and walkerettes, that they be appropriately matched to ambulation needs and individually height adjusted. A working call system, e.g., light or bell signal, should be accessible so that those patients able to understand can seek assistance as needed for toileting desires.

The toilet itself should be a pleasant and comfortable room with attention to color contrast, lighting, and cleanliness. Toilet seat inserts for those patients with arthritic hips will elevate seats for ease in sitting and rising. Grab bars or frames will aid such activity and promote safety.

Fecal impaction has been described as a common cause of urinary incontinence.[85] A stool mass in the rectum exerts pressure across soft tissue to obstruct the bladder outlet causing the bladder to distend with subsequent overflow incontinence. A study of incontinence amongst women in a psychiatric hospital with average age 77 years found that 26% had fecal impaction and 19% chronic constipation prone to cause impaction.[45] The author recommended a daily record of patients' bowel action, a high residue diet, and a daily fluid intake of 2,500 milliliters.

In older people bacteriuria is common with institutionalized men and women having similar prevalence rates (14-59%, 19-56%).[22] A study of institutionalized men with bacteriuria found incontinence in 81% and impaired mental capacity/dementia in 77%.[59] Amongst older women bacteriuria has been shown to be associated with precipitancy, i.e., the need to pass urine in a hurry.[12] Treatment of urinary tract infections in the elderly may not effect urine control but should be pursued for those with an initial bladder infection, advanced renal involvement, or febrile patients with upper urinary tract infection.[22]

UROLOGICAL DISORDER

Patients with cognitive impairment can be expected to experience incontinence related to known urological etiologies in the same proportion as other elderly. One study found that in a sample of 48 incontinent, institutionalized elderly, urological diagnoses did not differ according to cognitive impairment.[87] There is no evidence that Alzheimer patients are less likely to have difficulties with sphincter weakness, detrusor instability, prostatic hypertrophy, etc. Alzheimer patients, however, will be less likely to be able to compensate for the various types of incontinence. For instance, an Alzheimer patient is not likely to remember to keep her/his bladder empty. Rather, they must respond quickly as they sense that urine is leaking or that they feel an urgency to urinate.

Surveys of community living older women reveal that urine loss classified by symptomatology is most often stress urinary incontinence.[15,38,88] This condition, characterized by loss of urine on physical activity, is caused by urethral sphincter incompetence.[76] Two clinical studies of incontinent older women support the symptomatology surveys, finding stress incontinence the primary etiology.[21,34] However, in general clinical studies of incontinent elderly people have most often found urge incontinence (detrusor instability) the predominant cause of wetting.[17,23,26,62] This condition, characterized by loss of urine with prior intensive urgency, is caused by uninhibited bladder contractions.[83] These two common urological conditions, stress and urge incontinence, may occur in combination usually called mixed incontinence.[56] While sample size, selection, and measurement criteria vary across clinical studies, mixed incontinence, i.e., stress and urge, have been found in 1%,[23] 10%,[34] 17%,[21] and 32%,[26] of older people.

Two other types of urinary incontinence are commonly noted: overflow and functional.[32] Overflow incontinence is characterized by continuous small volume urine leakage and is symptomatic of an overdistended bladder.[20] While there are a variety of causes for this condition, in the elderly male, enlargement of the prostatic gland is the most common.[79] Functional incontinence refers to involuntary urine loss in individuals who apparently have normal urological function but who are unable to reach the toilet in time due to mobility, cognitive, psychological or other problems in combination or as singular entities. Notice that both these last two "types" of incontinence are really symptomatic rather than diagnostic labels. Overflow incontinence is a non-specific term and requires evaluation for the underlying cause. Functional incontinence is even more non-specific and should not be used as a diagnosis unless an appropriate evaluation has been done and pathological processes ruled out.[20]

In summary, older patients with cognitive impairment may have the common urological disorders for their age group, i.e., stress incontinence in females and overflow incontinence due to benign prostatic enlargement in males. In addition, cognitive impairment arising from neurological damage is likely to affect central nervous system bladder control and result in urge incontinence, (detrusor instability).[12] Therefore, the cognitively impaired older person may have several urological causes for urinary incontinence.

COGNITIVE DISORDER

Jirovec and Wells found of 61 nursing home residents with chronic memory difficulties, incontinent patients scored significantly lower on three measures of cognitive ability.[42,43] When the incontinent patients were divided into those who were sometimes continent and never continent, cognitive ability decreased significantly as urine control decreased. Low cognitive ability scores are associated with urinary incontinence. Cognitive impairment does not in itself cause incontinence until the late stages of Alzheimer's disease. Several researchers, however, have demonstrated the association between cognitive impairment and incontinence.[8,15,36,40-43,57,61,73,75] In Alzheimer's disease, the cognitive deficient can contribute to urinary incontinence.

As impulses reach the cerebral cortex from the bladder, the person becomes aware of the need to urinate. At that moment the individual must be able to adequately interpret the meaning of the impulse from the bladder in order to consciously inhibit urination. Problems can arise if the patient does not understand the meaning of the sensations he or she is experiencing, what the proper response to the sensations should be, where to go in response to a full bladder, or how to remove clothing and assume the position needed to maintain urine control. These are learned behaviors which are subject to memory loss.

Many of the changes in Alzheimer's disease are related to memory losses.[14,82] Pearce and Miller found that 100% of patients with senile dementia experienced memory problems early in the disease.[63] The hallmark of Alzheimer's disease is impairment of recent memory. In the early phase, the patient also evidences decreases in social graces. This in part may be the result of the patient forgetting how to act with other people. Social norms are taught by society. It is not unlikely that they would be forgotten. The patient's inability to focus on important events may be related to the patient's difficulty in remembering what is or is not important. Evaluation occurs by comparing to past experience. In that way people categorize and place events into perspective. In Alzheimer's disease, the richness of the data available to the individual for comparison purposes decreases. The Alzheimer patient is less able to identify events that warrant attention.

Urinary incontinence in Alzheimer's disease is likely to be at least partly a cognitive disorder. As the memory impairment increases the patient may forget where the bathroom is located, how to remove clothing in order to toilet, or how to respond to the sensation of a full bladder. The result may be loss of urine control as the bladder empties before a toilet is reached.

BEHAVIOR DISORDER

Urine control may also be viewed as learned behavior. Established behavior patterns can be influenced throughout life. Learning, in fact, occurs in complex situations where an individual and the environment influence each other in a reciprocal, continuous interactive process.[7] As a person encounters different environmental stimuli, cognitive processes estimate the probable consequences of various responses. Responses are selected based on expectations derived from previous experiences.

Much of the incontinence seen in the cognitively impaired occurs in nursing homes. This type of patient may learn through direct experiences and the experiences of others that they are expected to assume the role of "patient", and patients "wet." The nursing home staff approach the problem of incontinence with resignation. They do not indicate to the cognitively impaired that urine control is an expected behavior. In fact, methods to handle the incontinence problem are quickly instituted. Seldom does handling the problem include some mechanism to compensate for the cognitive deficit while still maintaining continence. Frequently, part of the problem solution, diapering the patient, makes it more difficult for the patient to use the toilet since removing the diaper is often troublesome. After initial episodes of incontinence that result from the patient's inability to remember things that are necessary to responding appropriately to a full bladder, the cognitively impaired may learn that further attempts to control urine are futile. The environment is structured to manage the incontinence rather than maximize continence.

Residents within nursing homes are often expected to assume the role of a patient. The environment generally facilitates the "sick role."[54] The behavioral deficits often seen in nursing home residents are partly a function of the nursing home environment and its concomitant experiences.[37] McClannahan identified a number of environmental characteristics within nursing home settings that influence motor activity, verbal behavior, and self-care ability.[55] A review of several studies demonstrated the importance of environmental factors in influencing resident's behavior.

Lester and Baltes studied nurse's verbal responses to various patient behaviors in a nursing home.[51] Dependent behaviors were most often reinforced with a positive verbal response by the nurse. In contrast, independent behaviors by patients were usually followed by no verbal response. In a second study patient behaviors were categorized as either dependent or independent. Staff behaviors were categorized as responses that encouraged dependency (dependence supportive) and responses that encouraged independence (independence supportive). They found that dependent behavior by elderly residents was most frequently followed by dependence supportive behaviors by the staff. Independent resident behavior was not followed by independence supportive staff behaviors.[9]

Sperback and Whitbourne addressed the issue of nursing home environments directly by training nursing home staff to be aware of patient dependency.[72] Three experimental groups were utilized. Staff caring for the four subjects in the first group were given dependency awareness training, were taught behavioral techniques, and were impressed with the importance of response contingencies in changing behavior. For the two subjects in the second group the staff caring for them were given only the awareness training. No training was given to staff caring for the two patients in the third group. Three of the four patients in the fist group increased their independence while the other groups remained unchanged. Self-reports by staff showed that staff in the first group greatly decreased the time they spent reinforcing dependency. Other studies have shown that changing environmental contingencies can alter behavior of elderly nursing home residents in areas related to self-care,[29] eating behavior,[4,5,6,27] activity level,[54,57] socialization,[53] and memory.[50]

The experience of patients being cared for at home while less extreme is often similar. The home environment is not designed to manage a patient with urine control problems. Family members often attempt to contain the incontinence in order to protect home furnishings. Health professionals working with families offer little advise related to decreasing the incontinence. Almost no research has been done on decreasing incontinence in Alzheimer's disease. Most frequently the family becomes overwhelmed and relunctantly places the Alzheimer patient in a nursing home. Incontinence is a common cause of admission to a nursing home.

EVALUATION

Evaluation of urinary incontinence in the cognitively impaired institutionalized elderly includes determining the history of the problem, providing a physical examination, providing selected urological tests as appropriate, and analyzing the environmental situation.

HISTORY

History gathering is a basic part of clinical evaluation; it is a process of listening to a patient's complaints and asking relevant questions about past health, current health, and symptoms. Obviously this process can be very difficult in the cognitively impaired institutionalized elderly. Because of this, some clinicians might dismiss history gathering as non-productive and not essential to the immediate problem of incontinence. While this view can be appreciated, we believe that attention to all phases of history gathering is useful. The clinician can gain a better insight into the patient's difficulty and also demonstrate to care providers the importance of a meaningful data base. Insight may improve both diagnosis and treatment/management plans. Demonstrations of data needs may generate more, provide interest and participation.

Dependent on the degree of cognitive impairment, the elderly incontinent person may be able to understand and answer correctly, questions about both the past and present. This initial interview provides a picture of the patient's perspective, which, while it might fluctuate, gives guidance to other evaluation steps. Attention must be paid to the usual history/interview procedure with privacy provided and support of significant others as needed (e.g., a family member or trusted staff person). A warm, friendly, patient, listening approach is useful. The major goal of the patient interview may be more development of trust and understanding than clinical facts.

A meaningful point to start is awareness of voiding difficulty, e.g., Clinician: "I understand you have been having trouble controlling your urine and have been wetting your clothes. Is that true?" "Yes" responses should be followed with "tell me about it" or "What is the problem?" "No" responses should be followed with probes which also become subsequent questions for those who seem to have awareness: "Can you tell when you have to pass your urine?" "Can you get to the toilet in time?" "Does it burn or hurt when you pass your urine?" Of course many patients cannot answer these questions, and the point is not to frustrate or worry them but to establish a relationship. It may be clear in a few minutes that at this time useful answers are not forthcoming. In that instance, clarification of the Clinician's next evaluation step takes place, e.g., "Well, I am going to give you a check up" (proceeds to direct for urine sample or physical examination). Those who can answer questions in a sensible way may be asked to provide more symptoms or past history. Care should be taken not to fatigue or anger the patient.

Questions should be asked throughout the physical examination because this interaction helps to build a relationship and diverts the patient who may become restless or frightened. Also, patients may recall the past better when questions are focused on specific observations arising from the physical examinations, e.g., Clinician: "I notice you have had an operation. What was that?" Again, patients may or may not know, but the question is more meaningful at that point than asking abstractly during the interview: "Have you had any operations?".

Apart from the patient history ,data are available in the institutional record for the patient. Important information may include current medications, drug sensitivities, physical examinations and laboratory findings, and nursing staff observations. However, on the whole, patient records in long term care may be a poor data source, but reference may be made to acute care institutions or private physicians. With patient, guardian, or other permission as appropriate, these other health care sources should be contacted for urological, neurological, and gynecology data as necessary. Useful information to ascertain includes details of prior: urological/gynecological surgeries, urological/neurological evaluation, urological treatment, and drug sensitivities.

The patient's family and/or significant other may be able to supply details or source referral for relevant past history. Those who have lived with or had close contact in the recent past might be aware of the patient's voiding pattern history or at minimum, past social response to toilet needs. Useful questions include details about any day or night incontinence episodes, nocturia frequency, (bladder needs awaken the person at night), day toileting urgency/frequency, and the person's typical attitude to urine control, e.g., shameful, embarrassing, or forthright.

A critically important data base is the nursing staff providing the patient's care. Interviewing such staff is superior to reading record notes which usually are too summarized to be helpful. Ideally, talking with staff from all time periods provides the best picture. At minimum, discussion with the primary day staff is essential. Important questions include: Do you think she/he can tell when they have to pass urine?, How often do you find she/he wet-day/night?, How wet?, Do you take she/he to the toilet-how often?, Does she/he use the toilet?, Why do you think she/he wets?.

Most long term care institutions do not provide fluid intake-urine output records on patients. However, most staff can be persuaded to gather such data for a short period of time, i.e., 3-4 days. This short period, if planned and praised, provides a good picture of the problem and is probably quite reliable. Such a recording can be a very simple time-volume notation, but increases usefulness if combined with two-hourly routine checks, fluid descriptions, voiding action (toilet, commode, incontinent), and prior toileting behavior (e.g., asked to go to toilet, restless, etc.).[3,19]

PHYSICAL EXAMINATION

Physical examination starts with obtaining a clean voided urine specimen which can be spun down in a centrifuge and examined with a light microscope. Our Continence Clinic protocol has set white blood cell counts of 10 or greater per high power field (hpf), the presence of red blood cells per hpf, and/or significant bacteria as positive findings which require a catheterized urine sample for validation. Confirmation of any of these findings in a catheterized specimen requires it to be sent to a laboratory for culture of the organisms and testing of sensitivity to drug treatment.

Obtaining a urine sample in a cognitively imparied individual requires careful consideration of the patient's mood as well as usual degree of cooperation. The instruction necessary for obtaining a satisfactory sample is usually too frustrating to the patient or is such that she/he simply cannot follow the steps required. It is far more efficient and helpful to the patient to either provide close supervision and assistance as needed or do the steps for the patient directing her/him in the sequence. For patients in whom this is not possible catheterization for a specimen is the best approach. It is a waste of time and a source of considerable patient irritation/discomfort to try to obtain clean voided specimens in those who cannot cooperate. Yet, these individuals may be most in need of urinalysis because an underlying urinary tract infection may be causing or making worse their uncooperative behavior.

Catheterization of mentally impaired patients should be done with consideration of standard procedure, e.g., privacy, comfort. In many cases a single examiner with a trusting, cooperative patient can manage the technique alone. However, it is best if two clinicians complete the task, one to obtain the specimen and one to be at the patient's side to divert, comfort, or prevent disruption. If more than two clinicians are thought necessary for the task, consideration of selecting another time when the patient is apt to be more cooperative or giving a medication which will elicit more compliance or less resistance is best. In our experience providing time for a relationship between the clinician and the patient and attention to warm and caring behaviors on the part of the clinician to the patient minimizes catheterization problems.

This same caring and attentive manner carries over into the remaining parts of the examination. The patient can be examined at the bedside, but this is not always best because of threats to privacy, noise distractions, poor lighting, and poor positioning for both the patient and examiner. A properly equipped examination room is the best place to conduct the initial physical evaluation.

Examination may focus on only the essential parts of a urological evaluation, i.e., abdomen and genitalia, but is best if it includes a more comprehensive evaluation to check for underlying chronic or acute illness as well as related functional disorders. Knowledge of current health status is a fundamental basis to determining the cause of urological difficulties. Further, exclusive and immediate focus on the patient's most private body parts may be perceived as frightening or anxiety provoking, fostering uncooperative behavior.

Careful explanation and direction to the patient is essential. The patient should toilet before the examination. She/he needs to remove regular clothing and wear an examination gown which provides cover while allowing easy access to parts of the body. Depending on cognitive ability, patients can usually independently undress or participate in this activity. Undressing time provides a further opportunity to continue building a trusting relationship. Assistance may be needed to get onto the table. Approximately half the examination occurs while the patient is sitting at the end of the table and half while lying on the table. Initially the position is sitting and the examiner evaluates blood pressure, pulse, vision, hearing, heart, lungs, musculoskeletal and neurological aspects. This patient position and examiner focus provides time to further evaluate patient response to touch, instruments and direction. The examiner needs to explain while evaluating and to praise cooperative behavior and/or signs of good health.

The patient is then asked to lie back on the table with attention paid to comfort, e.g., pillow and back adjustment, a blanket/sheet cover. The abdomen is checked for scars which may relate to previous urological surgery and bladder distention which pertains to retention of urine. The examination then varies; the female will need a pelvic examination, the male a prostate examination. Be sure of good lighting and readily available equipment before positioning the patient. Often a single examiner who has established patient trust can continue the evauation alone. If in doubt of patient compliance or particular anxiety another clinician should be at the patient's side for the remaining examination.

Females who do not mind table stirrups will be most comfortable with shoes and stockings on and good leg coverage provided. Those with arthritic hips may prefer not to use the table stirrups. Patience in determining the best position for the female will be rewarded by a more efficient examination. Again, explain everything to the patient and continue to interact, asking about comfort or symptoms. Visually evaluate the perineal skin, noting color changes, growths, or other abnormalities. Examine the urethra for urethrocele and/or caruncle. Ask the patient to bear down or cough to determine if there is stress urine leakage. Catheterize the patient for residual urine at this time. Although such catheterization is best immediately after toileting and may in this process be 15-30 minutes later, a better examination sequence and relationship occurs for the patient. Normal urine residual should be less than 100 millileters but diuretic and other medication effect need to be considered. The residual urine obtained is a useful specimen for analysis and/or culture and sensitivity for those in whom a prior specimen has been difficult to acquire.

After the catheterization, visually inspect the introitus for stenosis, discharge, or evidence of prolapse, (cystocele, rectocele, uterine). Proceed with a manual examination, having lubricated well the gloved finger(s). Explain and be gentle so as not to elicit pain. Those women with severe vaginal stenosis may not be able to emit or tolerate a single finger manual examination. No further pelvic evaluation is possible for them. Women with moderate stenosis which permits a single finger examination may be able to have the evaluation continued by use of one half a small disposable clear plastic speculum. The remaining women can be examined with the full speculum but, again, this is usually a small size, well lubricated.

This manual and/or visual examination of the vagina and cervix permits a better assessment of tissue health. Senile vaginitis is common in older women. Our clinical experience with cognitively impaired women suggests that the prevalence of severe vaginitis in this group may be greater. Such women seldom complain of discomfort even during a pelvic examination. However, atrophic vaginitis and urine control are associated with improvement in both related to estrogen treatment.[67,80]

The pelvic examination also provides detail of structural alteration, i.e., prolapse which may relate to loss of urine control or discomfort in general. While the discovery of a possible need for surgery might not always result in a viable option for such, it provides a more meaningful data base for alternative therapies. In the cognitively impaired female it is especially important to provide a vaginal evaluation to rule out the presence of a pessary. Pessaries are soft rubber devices of various shapes which are inserted into the vagina to provide support and reduce structural prolapse. They are usually removed nightly for cleansing and tissue rest. Correctly inserted they can improve types of stress urinary incontinence. Incorrectly inserted they can obstruct urine outflow with such women commonly presenting with a urinary tract infection, painful urination, and discomfort. In some women long-forgotten and unattended to pessaries become incarcerated and may cause infection or fistulas.[65] The institutionalized mentally impaired may not remember use of a pessary in the past and institutional records with a tendency to omit pelvic examination in older women in general and the cognitively impaired in particular may be incomplete.

The evaluation of the female is completed with a rectal examination to determine impaction or constipation as possible urine control factors.

Male genitalia are initially examined while the patient is lying on his back on the table. Visual evaluation of the perineal skin is made with attention to skin color, rash, growths, or discharge. Note is made if the penis is retracted (sunk into the surrounding tissue) and if the patient is circumcised. For males with penile foreskin, the foreskin should be retracted and checked for ease of movement and cleanliness. The scrotum is examined for size, symmetry, and tenderness. Catheterize the male patient at this point to determine the volume of residual urine.

The patient is then turned onto his left side and with his right leg drawn up to his abdomen, has a rectal examination. This provides evaluation for impaction and constipation but also it permits assessment of the lower one third of the prostate gland for size, consistency, and tenderness. This prostate check is both a screening for carcinoma as well as acute inflammatory conditions. A normal prostate on rectal examination does not rule out prostatic hypertrophy of the gland lobes unable to be assessed in this manner.

At the end of the physical examination both general health and urological structural status are known within the limits of clinical evaluation. In combination with history, a clinical diagnosis can be made. Such a diagnosis is impressionistic and for treatment which carries considerable risk, e.g., surgery, further urological testing should be done. But for many patients and for most of the cognitively impaired the clinical diagnosis is often sufficient to institute immediate treatment. Therapies may carry little or no risk and be very successful. In those for whom therapies fail, further testing might be beneficial but only in balance with realistic treatment options.

UROLOGICAL TESTS

There are a large number of urological tests available. These should be carefully selected by a qualified urologist with consideration of the clinical diagnosis and realistic treatment options. A simple, non-invasive test is uroflowmetry in which the patient sits (female) or stands (male) to void into a device which profiles the characteristics of urine flow. Abnormal urine flow patterns can help detect bladder dysfunction, outflow obstruction and bladder-sphincter dysfunction.[2] However, most tests involve instruments passing along the urethra and into the bladder. Patient cooperation is essential not only to avoid tissue damage but to follow directions as part of the tests. For these reasons and because treatment options are not thought to change, invasive urological tests are not common for the cognitively impaired. However, if patient cooperation is possible, modest testing should be done because treatment options indeed may change.

Totterman tested twenty-four institutionalized incontinent patients, most of whom had moderate to severe mental impairment, with cystometrics.[75] This test involves catheterization and bladder filling with fluid or gas to determine capacity and filling dynamics. Fifty-four percent of his sample had uninhibited contractions (urge incontinence) suitable for medication treatment; the remainder had normal studies, suggesting a functional type of incontinence appropriate for behavioral therapies. Soybein and Awad did cystometric studies on thirty institutionalized memory impaired males.[73] They found that twenty-four had detrusor hyperreflexic (urge incontinence) and four had normal bladders; all these were treated with behavioral therapies and a few with medication added. Two patients had hypotonic bladders which required individual treatment. Thus, cystometric evaluation is a very useful urological test. The reported studies reveal a patient compliance range of 48-89% for the cystometric test. The lower percentage is a mix of both non-consent from the patient and his family.[73] While the higher percentage is noted in a study which does not report consent per se'.[75] The possibility exists that some cognitively impaired patients might tolerate the procedure well but are restricted from such testing by family concerns.

THE ENVIRONMENTAL SITUATION

The environmental situation includes consideration of people, space, and equipment within the sphere of the cognitively impaired individual. Among the institutionalized these factors may be limited: shortage of staff, crowded space, inadequate or insufficient equipment. Even with a reasonable amount of all these factors a pervasive negative atmosphere may be predominant because of the incompetency associated with the mentally impaired.

If such patients try to walk around alone, even to go to the bathroom, they are often restrained. Rather than being allowed to dress themselves, they are often dressed. Research has shown that individuals can erroneously infer their own incompetence from situational factors. One experiment involved three phases.[49] Initially, college students successfully performed a two-part task. Subjects were then paired and randomly assigned the label of assistant or boss. The pairs were asked to work together to complete a task similar to part two of the first task. In the final phase, subjects again were asked to complete a task similar to part one of the first task working alone. Subjects who were labeled as the assistant in the second part did only half as well on the third task when compared to the corresponding part they completed on the first task. It was thought that these subjects inferred thier own incompetence from interpersonal situational factors. When labeled as less competent, they came to believe in their own incompetence. Subsequent behavior reflected those beliefs.

Social breakdown theory supports the effects of the nursing home environment on residents. The theory suggests that an individual's sense of self, ability to interact with the social environment, and feelings of self-efficacy are related to the social labeling processes experienced.[48] When people are deprived of important roles, normative information, and reference groups, they are especially vulnerable to labeling processes. Entering a nursing home is atypical. The new resident is expected to give up most previous roles and assume the role of patient. Usual norms regarding her/his behavior are no longer applicable and usual reference groups are gone. A new resident sees others spending the day doing little, often still in pajamas and a robe. Some residents are restrained and incontinent. According to social breakdown theory, a syndrome ensues whereby the elderly person begins to believe he or she is like the other residents. As a result, many behaviors are not attempted and skills atrophy. This results in the resident demonstrating the incompetence he or she has come to believe of themselves.[48]

It is important then to evaluate the environment for passive, negative messages. Useful questions to pursue include: Is there a dominant urine smell? Are patients dressed appropriately in day clothing during day hours? Are incontinence pads (blue pads) and/or diapers easily visible? Are meaningful activities evident? Are there homey and attractive furnishings?

Use of clothing or chair restraints should be explored. Sometimes their use reflects a safety need arising out of poorly designed equipment, e.g., too high and too deep a chair, which can be corrected. At other times their use reflects a realistic desire to limit wandering behavior but with little consideration of possible alternative strategies and/or the need to regularly provide exercise and toilet access. Jirovec and Wells found that urine control differed significantly according to whether the memory impaired patient was more or less mobile.[42,43] Continent patients with some type of chronic degenerative brain disease could walk faster, walk farther, and balance longer than incontinent patients. Continent patients needed less help in walking and were better able to get out of a chair alone when compared to incontinent patients. When patient variables were used to predict if the patient would be continent or incontinent, mobility emerged as the first predictor for the urine control group. If the patient could get to the bathroom alone, the patient was likely to be continent. If the patient needed help getting to the bathroom, the patient was most likely to be incontinent. A patient who is diapered, restrained in a chair, and not released and helped to the bathroom is likely to conclude he/she is not expected to use the bathroom. When repeated attempts to rise from the chair are unsuccessful the patient is likely to give up all attempts to toilet. An environment that limits patient mobility can be especially detrimental to maintaining urine control.

TREATMENT

Treatment of urinary incontinence in the cognitively impaired elderly relates to understanding the cause of the incontinence. Active treatment follows active evaluation and may include pharmacological, behavioral, or surgical approaches in a singular or combined manner.[32] Attention to enhancing mobility may be a significant treatment to effect urine control. In addition external equipment is available to help manage wetting episodes, e.g., protective pants.[32] Unfortunately, care of the cognitively impaired incontinent elderly is commonly directed solely to passive management of wetting episodes.

Pharmacological treatment for urge incontinence (detrusor instability) is most often anticholinergic medication, e.g., propantheline (Pro-Banthine). Such medication works by either competing with Acetylcholine at the post ganglionic receptors or by interrupting transmission at the ganglion level.[10] Yet, reduction in Acetylcholine-medicated transmission of impulses has been posed as a hypothesis to explain Alzheimer's disease.[86] No study has been done to evaluate the effect of anticholinergic medication on cognitive impairment. However, many drugs other than those prescribed for urge incontinence have anticholinergic effects and the risk of anticholinergic toxicity in the elderly is of concern in general.[11] In practice, low dosage monitored treatment with anticholinergic medication for urge incontinence in cognitively impaired elderly persons tends to improve urine control and has not appeared to increase cognitive difficulty.

Pharmacological treatment for stress incontinence is most often with alpha-adrenergic agonists, e.g., Phenylpropanolamine hydrochloride (Rhindecon) but these medications can increase blood pressure and have other side effects including nervousness and insomnia.[10] There is no study of use of this medication in the cognitively impaired elderly. In the Continence Clinic we rarely prescribe this type of medication for such patients. A possible exception is Imipramine (Tofranil) which is primarily a central nervous system depressant used as an antidepressant but which includes both anticholinergic and alpha-adrenergic agonist properties.[10] For selected cognitively impaired elderly the drug may improve urine control.

Behavioral manipulation effect on the toileting behavior of cognitively impaired elderly has been demonstrated by several researchers. Terminology is not standardized for these treatments. It may be helpful to understand behavioral treatments from the most simple to the complex. Scheduled toileting is a staff routine to take patients to the toilet at fixed intervals whether or not the patients desire to toilet. The schedule is usually set at two hour intervals throughout a twenty-four hour day with commodes used as toilet substitutes during the night. This is probably the most common behavioral program in institutional care. Toilet retraining is a slightly more complex behavioral treatment in which observations are made of the individual's fluid intake and toileting desire/wetting episodes with an effort to match the toileting program to the individual's pattern. Behavioral modification is the most complex treatment with an individualized selection of rewards for appropriate toileting combined with the individualized fluid intake/toileting performance pattern. A system of specific reward for correct toileting and withholding of reward for wetting enhances and reinforces the desired behavior.

Sogbein and Awad used scheduled toileting, called "a timed-voiding routine," in a sample of cognitively impaired men.[73] Attention was given to day toileting only at two hour intervals. Eighty-five percent of the twenty patients with hyperreflexia (urge incontinence) reduced their incontinence to less than 20% of the time.

King used psychogeriatric patients to study urine control.[46] Fifteen patients selected from various wards were moved to a new trial ward where regular toileting was initiated with a variety of other interventions. Urinary incontinence was decreased for all but one of the subjects.

Toilet retraining has been used with an informal system of rewards. Clay attempted to reverse incontinence with four elderly with some type of dementia. Toilet retraining was used with social reinforcement and self-reinforcement.[18] Two of the four patients improved; one was completely continent with reminders; and one did not improve.

Behavioral modification has been most studied. Sanavio used a repeated treatment design with two elderly with senile dementia in long-term care.[68] Environmental contingencies were related to soiling versus toileting. These were alternated with consequences not contingent on toileting behavior. Both patients improved when the consequences were contingent on their behavior. Pollack and Liberman did a similar study with six geriatric patients with chronic brain failure.[64] However, reinforcements and punishments were given irregularly. The result was no improvement in any of the patients. Two of the patients worsened.

Schnelle, Traughber, Morgan, Embry, Binion, and Coleman studied 21 incontinent geriatric nursing home residents with some type of physical limitation.[69] Using randomly assigned experimental and control groups, all patients were checked for wetness on a regular basis. The experimental group was prompted to toilet at each check and was given social approval or disapproval at the check depending on if they were wet or dry. Patients were not toileted unless they requested help when prompted. This required the patient's involvement in the toileting procedure. At the end of the 21 days of treatment, the experimental group was significantly less incontinent and requested toileting more frequently than the control group. Clay also attempted to reverse incontinence with four elderly with some type of dementia. Habit training was used with social reinforcement and self-reinforcement.[18] Two of the four patients improved; one was completely continent with reminders; and one did not improve.

Other researchers have studied the effect of behavioral manipulation on urine control using psychogeriatric patients. Grosicki studied the effect of social and material rewards using a non-random control group and experimental group.[30] There was no improvement for the experimental group, while the control group decreased incontinence. The appropriateness of the experimental manipulation could be questioned. Improvement in the control group would seem to demonstrate the impact of regular checks for wetness. Hartie and Black focused on nighttime toileting with social and material rewards if the bed was dry.[31] Using five long-term psychogeriatric patients, bed wetting was decreased by almost fifty percent.

Two researchers used long-term psychiatric patients to study incontinence. It probably can be assumed that some of their samples were patients with Alzheimer's disease. Carpenter and Simon employed four groups.[16] The three experimental groups were given habit training, habit training with social reinforcements, and habit training with material reinforcements respectively. The fourth group was used as the control group and given the usual care. The two habit training groups with reinforcements decreased in urinary incontinence. The control group's incontinence increased, demonstrating further the impact of environment on urine control. Wagner and Paul studied 35 chronic psychiatric patients.[78] After baseline data were collected, material and social rewards and long-term incentives to maintain continence were given. Thirteen of the patients became continent during the baseline period when they were being checked regularly for wetness. The other subjects demonstrated significantly less incontinence when compared to their baseline incontinence levels.

Thus, behavioral manipulation as simple scheduled toileting, combined with attention to the patient's voiding pattern (toilet retraining), and toileting with attention to contingencies (behavior modification) are useful therapies to improve urine control and/or reduce wetting in cognitively impaired institutionalized elderly. Behavioral therapies which focus on learning of exercise, e.g., bladder retraining and pelvic floor exercise are usually not successful in such patients because of difficulty concentrating and learning or remembering instructions.

Selected surgery may be helpful in some cognitively impaired elderly with consideration of overall health status and risk versus benefit ratios. Vaginal surgery as hysterectomy for severe uterine prolapse or cystocele/rectocele repair may be indicated and useful to some women. Prostate surgery as a urethral procedure (transurethral resection) may be helpful to some men.

Programs to increase mobility through exercise and improved environmental access may directly effect urine control in cognitively impaired institutionalized elderly. Patient should be exercised consistently and regularly. Restraints should be used sparingly and only in combination with an exercise program.

The exercise routine should effectively challenge the patient and should be implemented with an attitude toward maximizing patient capabilities. Mobility skills can quickly atrophy with this use. As getting the patient to the toilet becomes increasingly difficult for caretakers, toileting is less likely to be attempted. A better alternative is to work to prevent loss of mobility in the Alzheimer patient.

Management of wetting through use of external equipment is a helpful adjunct to more active treatment. Such equipment includes products for the individual to wear as well as those used to cover bed or chair. Obstructing devices such as the penile clamp are not appropriate for the cognitively impaired. Collecting devices are most often used for males in the form of condom drainage systems. This type of drainage has a variety of problems such as skin damage and is not always well tolerated. In addition urinary tract infection has been associated with patient lack of cooperation and condom drainage manipulation in short term use,[35] extended use in general,[44] and nosocomial infection.[24]

Absorbent products which resemble and fit more like ordinary pants are usually better tolerated and facilitate toileting in the cognitively impaired. Thus, washable pants with disposable inserts may be more useful than fully disposable products even though laundering must be carefully considered. A range of such products are available,[33] although none have had comparative trials with such patients in the United States.

Protective underpads for bed or chair are typically poor quality disposables. Consideration of available larger sized and improved quality disposables might yield greater patient comfort and greater efficiency. In addition washable underpads are available. One innovative design has had comparative studies which reported increased patient comfort, decreased skin redness, reduced bed linen changes, and reduced costs.[70,84]

Effective treatment for urinary incontinence begins with a questioning systematic exploration as to the cause of the lack of urine control. Dismissing such exploration as unnecessary or unproductive in the cognitively impaired is improper. Attention to physical, envirommental and behavioral factors will identify multiple possible etiologies which can be treated or resolved.

SUMMARY

Urinary incontinence in the cognitively impaired elderly has had little research in etiology, evaluation, or treatment. Amongst the institutionalized, translation of current and forthcoming knowledge into practice is dependent on adequate staff numbers to provide care, the knowledge level of such staff, and the professional leadership available.

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